



THE LOUIS DE LA PARTE FLORIDA MENTAL HEALTH INSTITUTE



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

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**Florida Medicaid Alzheimer’s Home
and Community-Based Waiver Program:
An Evaluation**

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

Executive Summary

In November 2003, the Florida Medicaid Program submitted a 1915 (b) (4) and a 1915 (c) waiver proposal to the Centers for Medicare and Medicaid Services (CMS). 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. The successful vendors for the program, hereafter referred to as the Medicaid Alzheimer's Program (MAP), were to develop a network of service providers to deliver direct services to recipients. Authorized services included: (1) case management, (2) adult day care, (3) respite care, (4) wanderer alarm systems, (5) wanderer identification and location programs, (6) caregiver training, (7) behavioral assessment and intervention, (8) incontinence supplies, (9) personal care assistance, (10) environmental modifications, and (11) pharmacy review.

Due to delays in program start up, the original plans for the evaluation of the program's effectiveness and costs were revised. In consultation with staff from the Florida Agency for Health Care Administration (AHCA), a revised evaluation plan was developed that used a mixed-method, non-equivalent case control design intended to make maximal use of both existing databases and evaluation opportunities made possible by the waiver. The sample consisted of 38 Medicaid recipients with Alzheimer's disease who had been enrolled in the program for three months or more, along with their caregivers. The actual number of participants studied varied depending on the data source used. The control group consisted of 90 participants in Florida's ongoing Aged/Disabled Medicaid waiver program. In addition to the data analysis, site visits were conducted to the two initial vendors who were in the early stages of program implementation, followed by a more intensive site visit to one vendor who had recruited sufficient Medicaid recipients and their caregivers to conduct analyses.

The major findings of this evaluation were:

- A process has been initiated to identify individuals with Alzheimer's disease who are eligible for MAP services.
- The number of individuals participating in MAP has been increasing.
- All of the MAP participants manifest marked cognitive decline, are dependent on caregivers to complete activities of daily living, and are in need of supervision. On average, their caregivers had been providing care for more than two years. These data indicate that the selection procedures are effective in identifying the target population to be served by MAP.
- The age range of individuals participating in MAP is currently between 65 and 92 years of age; 72.7% are female.

- Approximately 67% of the current participants are Hispanic; 12.1% are African American.
- Comprehensive care plans were prepared for all MAP recipients whose charts were reviewed.
- The short-term evaluation of care plans and service plans suggest that MJHHA case managers are tracking and changing care plans in response to recipient needs.
- Among the caregivers, approximately 58% are adult children of the individual affected by Alzheimer's disease, and 42% are spouses. Approximately two-thirds of the caregivers are women.
- Slightly fewer than half of the caregivers reported being in fair to poor health.
- Nearly three-fourths of the caregivers reported being satisfied with life, yet 45% reported they often felt helpless. Approximately one-third provided responses that suggested they may have a depressive disorder.

While this study was based on a small sample from a program that is still in the process of achieving full implementation, the early results are encouraging. For example:

- Ten of the eleven caregivers who responded to a survey reported that they are either somewhat satisfied or very satisfied with MAP services.
- All eleven caregivers responding to the survey indicated that MAP services improved the quality of life for the caregiver.
- Preliminary data suggest that the costs of MAP are significantly less than those associated with the Aged and Disabled Waiver Program.
- Given the intensity of the recipient and caregiver needs, the services offered through MAP were judged to be extremely well targeted.
- The intensive site visit with one vendor suggested that, even at this early stage of program implementation, MAP is having a positive effect on recipients and their caregivers.

Due to the time required to establish a sustained impact on recipients and caregivers, it is still too early to assess the efficacy of some of the services provided. For example, caregiver training must be measured for its effectiveness over time. The impact of MAP on the well-being of recipients and their caregivers will also require a longer period of time to assess. Likewise, more time is needed to determine if MAP reduces the probability of institutionalization.

From a fiscal perspective, MAP compared favorably to the monthly costs incurred by Medicaid recipients with Alzheimer's disease who were participating in the longstanding and much larger Aged and Disabled Waiver Program. When extrapolated to a 12-month period, the costs were substantially less than those that would be incurred if the Medicaid recipients were to be placed in a nursing facility.

Recommendations and Policy Implications

1. The early implementation of MAP suggests that it holds promise for providing services to individuals with Alzheimer's disease and their caregivers. It is recommended that these preliminary findings be verified in future studies. In addition, it is recommended that the long-term outcomes of MAP be assessed over time.
2. While most caregivers reported they were satisfied with life, many caregivers reported they were heavily burdened by the demands of the caregiver role. More than a third of the caregivers had scores indicative of possible depression during the period when they and their family members were enrolled in MAP. This finding suggests that, in addition to caregiver training, caregivers may be in need of services to handle the stresses and strains they face on a daily basis. It is suggested that consideration be given to adding mental health services for caregivers as an additional service.
3. One recommendation for future consideration is to extend programs such as the Alzheimer's disease Medicaid waiver program to recipients with all forms of dementia. While Alzheimer's disease is the most prevalent form of dementia, it is not the only disorder that places great stress on families and caregivers.
4. A related recommendation is to review the feasibility of taking Medicaid recipients with any form of dementia out of institutional programs and moving them back into the community if they and their families are willing and if their levels of need are compatible with home or community placement. A policy of community reintegration for persons with dementia would be commensurate with the Olmstead Act and is made possible by the existence of programs such as Florida's Medicaid Alzheimer's Program.
5. It is recommended that AHCA review current provider enrollment procedures and the approval of Medicaid recipients for participation in the Alzheimer's disease waiver program to ensure timely access to the program.

Background

In November 2003, the Florida Medicaid Program submitted a 1915(b) (4) and a 1915(c) waiver proposal to the Centers for Medicare and Medicaid Services (CMS) for a Medicaid Alzheimer's Home and Community-Based Waiver Program. After obtaining CMS approval, the Florida Agency for Health Care Administration (AHCA, 2004) issued a request for proposal wherein they stated that the intent of the Florida Medicaid Alzheimer's Home and Community-Based Waiver Program was "to assist persons with Alzheimer's disease (AD) to remain in the community and maintain their functioning as long as possible by providing supportive services to the recipients and their caregivers." To that end, in August 2004, a vendor was selected to serve Miami-Dade and Broward Counties and a second vendor was selected to serve Pinellas County. A third vendor was selected during the summer of 2005 to serve Palm Beach County. Vendors for the Medicaid Alzheimer's Program (MAP) were expected to:

- Develop a network of service providers to deliver direct services to recipients. The direct services were to consist 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.

As of June 2006, the contracts for all three vendors (for Miami-Dade and

Broward Counties, Pinellas County, and Palm Beach County) had been approved. One vendor had nearly all of its subcontractors approved, and the second and third vendors were midway through the process. Only the vendor for Miami-Dade/Broward Counties had recruited a significant number of Medicaid recipients-caregivers dyads. As of June 2006, this vendor had more than 40 dyads enrolled. Due to delays in implementation, AHCA requested and received approval from CMS for a one-year extension. That extension ends in February 2007.

Statement of the Question

The main question addressed in this evaluation is whether or not the 1915 (b, c) Home and Community-Based Services (HCBS) Waiver Program is successful in providing quality services to the target population in a cost-effective and budget-neutral manner and is meeting its stated goal of allowing recipients to remain at home longer than they would without the waiver program services. Because of the small numbers of individuals who have been enrolled in the program (fewer than 50) and the relatively short period of time they have participated in the program (less than six months), it is not yet possible to determine if MAP has been successful in increasing the recipients' length of stay in the community. It is also not yet possible to fully address the question of cost effectiveness and budget neutrality. However, preliminary data provide several positive indications of program effectiveness and cost neutrality.

Alzheimer's Disease: The Challenge

Over the past five years, Florida's Medicaid costs have increased an average of 12.5%. Spending has increased from approximately \$5 billion in 1994 to more than \$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 Medicaid recipients are elderly. However, this relatively small percentage of elderly recipients incurs a disproportionate share of expenses. Approximately 21.2% of Medicaid dollars for Florida are expended on elderly recipients.

Five observations emphasize the importance of the Medicaid Alzheimer's Program and its explicit goal to affect a delay in the institutionalization of Alzheimer's disease patients in long-term care:

1. Approximately 420,000 elders diagnosed with Alzheimer's disease are currently living in Florida, a substantial increase from the 370,000 estimated in 2001 (OPPAGA, 2001). A significant majority (approximately 70 to 75%) of this population lives at home and receives care from family or friends whose burden increases as the dementia progresses and as care demands become more challenging.
2. People often live from 10 to 15 years after being diagnosed with Alzheimer's disease or other dementias (Kawas, 1999). Most spend a significant portion of this time being cared for by informal caregivers, with up to 80% of caregiving provided by family or friends rather than by health professionals. Increasing the time spent outside of an institutional setting by improving services

provided to Medicaid recipients and their family caregivers has the potential for significant cost savings.

3. The estimated prevalence of dementia in the long-term care population ranges from 50% to 70% (e.g., Kane, Ouslander, & Abrass, 2004).
4. Nursing home costs account for approximately 17% of the Florida Medicaid Budget, with expenditures well over \$2 billion annually (Crayton, 2004).
5. Medications designed to provide relief from symptoms associated with Alzheimer's disease are increasingly effective. For example, Edwards, Koumaras, Chen, Gunay, and Mirski (2005) found that Rivastigmine significantly reduced neuropsychiatric symptoms and behavioral disturbances in a sample of institutionalized persons with Alzheimer's disease over a one-year period.

With these points in mind, it is important to recognize that Alzheimer's is a progressively disabling disease, and services that are effective at one stage may be ineffective at another stage. Critical to successful intervention is a two-tiered system of screening which provides early detection, followed by more comprehensive assessment of cognitive deficits and probable diagnosis (Aupperle, 2006).

Of great concern is the fact that the majority of health care providers know little 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 creates a health disparities issue that is made more compelling by evidence that there is a higher age-specific prevalence of dementia 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., Ayalon & Arean, 2004). Compared to other racial/ethnic groups, some Hispanic caregivers may be at greater risk of caregiver burden and distress, while certain groups of Asian caregivers may be at lesser risk (e.g., Aranda & Knight, 1997). Identifying effective treatments for ethnic minority families is urgent, especially because 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.

The fiscal challenges of providing care to elders with multiple dependencies are immense. The cost of nursing home services alone is staggering. According to a Pew Center on the States (2006) report, roughly \$600 billion was spent on long-term care for elders from 1975 through 2004. On a yearly basis, the overall cost 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). More than 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.

Such figures pose challenges at state as well as federal levels. The need is real: as elders develop physical dependencies as well as the cognitive impairment associated with disorders such as Alzheimer's disease, they are less able to take care of themselves. To help frame the issues, the next section provides additional information on the nature and issues surrounding Alzheimer's disease.

Characteristics and Issues

Alzheimer's disease is the most common form of dementia. It is estimated that approximately 54% to 60% of persons with dementia diagnosed at age 65 or later have Alzheimer's disease (Lobo et al., 2000; Overshott & Burns, 2005) and that the same is true for 34% of persons diagnosed with dementia before age 65 (Harvey, Skelton-Robinson, & Rossor, 2003). Currently, more than 4 million Americans live with a diagnosis of Alzheimer's disease (Overshott & Burns, 2005), and by 2050, upwards of 12 million Americans will have such a diagnosis (President's Council on Bioethics, 2005). Globally, it is estimated that over 24 million people have Alzheimer's disease, with one new case being diagnosed every 7 seconds (Ferri et al., 2005). By 2040, it is estimated that there will be more than 81 million individuals with Alzheimer's disease in the world. In Florida, it is estimated that approximately 435,000 individuals will be diagnosed with this disease, representing 1 in 10 elders, a figure that is understandable in the context of Florida having the nation's highest proportion of individuals aged 65 and older.

One of the greatest challenges faced by family members and caregivers for individuals with Alzheimer's disease is the progressive nature of the disease itself (e.g., Brooks, 1993; Kane, Ouslander, & Abrass, 2004). One consequence of this progression is that the skills and knowledge attained by the caregiver continually need to be expanded as the cognitive capacity of the individual erodes. The trajectory of decline varies widely, although most patients will die seven to ten years post-diagnosis. However, onset of symptoms may commence up to 20 years pre-diagnosis (van der Flier & Scheltoens, 2005). Among the factors that may affect the rate of decline is the level of disturbance in cholesterol metabolism. In one recent, randomized clinical trial, the use of lipid lowering agents was found to slow the rate of cognitive decline (Masse et al, 2005; see also de Leeuw, 2005). Curiously, there is some evidence that people who are more educated manifest a faster decline (e.g., Mortimer, Ebbitt, & Jun, 1992). Based upon a prospective study of more than 300 patients, however, Scarmeas, Albert, Manly, and Stern (2006) concluded that individuals with higher levels of educational attainment have a greater cognitive reserve and that, as a consequence, diagnosis of Alzheimer's disease may come at a later stage in disease progression. There was no evidence that the rate of decline varied significantly across Hispanic, Black and non-Hispanic White participants.

A number of behavioral problems are associated with Alzheimer's disease. Wandering behavior occurs in more than 60% of individuals who have dementia, and it is often difficult for the caregiver and others to manage such behavior (Rabin, Mace, & Lucas, 1982; Kane, Ouslander, & Abrass, 2004). Wandering is poorly understood in terms of etiology, although there is recent evidence that differences

in cerebral blood flow may distinguish people who wander from those who do not (Rolland et al., 2005). Hallucinations, restlessness, paranoia, aggressive behavior and fright reactions are also common behaviors (e.g., Sink et al., 2006).

Empirical evidence supports the anecdotal impression that individuals with a dementia, such as Alzheimer's disease, are physically no sicker than other individuals their age. For example, Schubert et al. (2006) examined data from more than 3,000 primary care patients in Indiana and found that there was no significant difference, after adjusting for mitigating circumstances (age, race/ethnicity and gender), between patients diagnosed with dementia and those without dementia. The implication of this finding is that having a dementia, such as Alzheimer's disease, should not affect the incidence and prevalence of other health problems or the need for treatment of other conditions. While there is no known cure for Alzheimer's disease, there are a number of drugs that have been found to reduce its signs and symptoms. Of these, the cholinesterase inhibitors have to date formed the basis of most interventions, with Donepezil, Galantamine and Rivastigmine commonly used for mild to moderate levels of severity (Overshott & Burns, 2005).

Members of disadvantaged minority groups have generally been found to come to the attention of health professionals at later stages of many disease states. This is true for older as well as younger minorities. For example, Scarmeas, Albert, Manly, and Stern (2006) found that Hispanic individuals had more deteriorated cognitive performance at first diagnosis compared to their Black cohorts. An interesting finding was that for all individuals, those with more education had higher levels of cognitive performance at first diagnosis. Since both African Americans and Hispanics tend to have lower levels of educational attainment (e.g., Novak & Riggs, 2004), the deteriorated performance of minorities at first diagnosis could simply be an artifact of educational disadvantage.

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 keeping Medicaid recipients in the community. It is generally agreed that up to 85% of caregiving is done by family members (Kane, Ouslander, & Abrass, 2004). Moreover, there is evidence that the well-being and attitudes/motivations of caregivers are key determinants of nursing home placement. This is true not only in the United States but also in other countries. For example, in a study of a general population of older patients and their caregivers living in Spain, Argimon, Limon, Vila and Cabezas (2004) found that 1.5% of the individuals who were placed in nursing homes over the course of a year were more likely to have caregivers who had lower health-related quality of life scores on the SF 36 (a standard questionnaire originally developed in the United States). One of the reasons for their low scores may be the time and effort associated with caregiving of 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 a year. They found that even minor changes in cognitive status had an impact on caregiver time requirements.

Another element in the caregiver process that may be critical is the amount of information that 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 the caregiver. For this reason, researchers are studying the amount of information possessed by caregivers. Jarvis and Worth (2005) used a mail survey approach to examine both the prevalence of caregivers and their need for information. Approximately 6% of the participants indicated they were caregivers, and of those, 63% indicated they would like information relevant to that role.

Caregivers are universally acknowledged to play a vital role in keeping older family members out of institutions. Informal caregivers (those individuals considered to be family or friends who generally provide care with no reimbursement) constitute only one part of the social context that plays a role in the well-being of older family members. For example, those who provide emotional and tangible support to the caregivers are also important (Chiriboga, 2006; LoboPrabhu, Lomax, & Molinari, 2006). In addition, there is some evidence to suggest that the cognitive functioning of older persons suffering from Alzheimer's disease is enhanced by being part of a social network, regardless of whether or not a caregiver is present (Bennetta, Schneidera, Tange, Arnold, & Wilson, 2006). On the other hand, there is evidence that problem behaviors exhibited by persons with Alzheimer's disease may be exacerbated by the presence of caregivers who are overly burdened, depressed, uneducated, or younger (Sink et al., 2006).

There is also evidence to suggest that the level of caregiver stress may vary by gender of the caregiver. Specifically, there is evidence that men and women are affected differently by the role of caregiver. Although there are estimates that upwards of 70% of caregivers are female and one might anticipate that women are more attuned to the role of caregiver, there is also some evidence that women are in fact more stressed by the role (e.g., Chiriboga, Yee, & Weiler, 1992; Chiou, Chen, & Wang, 2005).

Study Issues/Hypotheses

As noted earlier, the primary question addressed in this evaluation is whether or not the 1915 (b, c) Home and Community-Based Services (HCBS) Waiver Program is successful in providing quality services to the target population in a cost-effective and budget-neutral manner and in meeting its stated goal of allowing recipients to remain at home longer than they would without the waiver program services. To address this main question, the following research questions guided the study:

1. How many persons are receiving services through the Alzheimer's disease waiver program?
2. What are the characteristics of service recipients?
3. What are the characteristics of caregivers?
4. What are the types of services provided? Are they appropriate to the needs of the participants?

5. How satisfied are family caregivers with the program?
6. Is the program meeting the budget neutrality requirements of the 1915 (b) waiver, and has the program generated cost savings?

Methods

This evaluation was originally designed to compare the cost and effectiveness of services provided to Alzheimer's disease patients and caregivers by the existing de facto service delivery system to the cost of a package of "best practice" services provided under the auspices of the Alzheimer's waiver program. Because of delays in the enrollment of recipients into MAP, it was determined that the original approach would not be feasible. The number of MAP participants was initially lower than originally projected but began to grow substantially in February of 2006. As a result, the number of cases in which Medicaid data on paid claim reimbursements was available was too small to conduct the original analysis.

After consultation with AHCA staff, the original evaluation questions and goals were revised. As revised, the evaluation would continue to use a mixed method, nonequivalent case control design to make maximal use of both existing databases and evaluation opportunities made possible by the waiver. The sample would consist of between 35 and 40 Alzheimer's disease patient-caregiver dyads who were anticipated to be enrolled in the waiver project in time for data to become available. The actual number of participants studied would vary, depending on the data source used. The individuals in the control group would, in turn, consist of participants in Florida's ongoing Aged/Disabled Medicaid Waiver Program. In addition, site visits would be conducted to the two initial vendors, followed by a more intensive visit to the one vendor who had recruited sufficient Medicaid recipient-caregiver dyads to conduct data analyses. The intensive site visit would provide a means of generating data by which to assess the fidelity of the vendor activities with respect to the activities and goals of the waiver program. In addition, three members of the evaluation team met with representatives of the three vendors at a joint meeting hosted by the contact manager, Ms. Beth Butler, from the Florida Agency for Health Care Administration. The purpose of this meeting was to make arrangements for procedures (such as selection of instruments to be used in the assessment of caregivers and recipients and the timing of the assessments) and to develop an agreement-in-principle for the use of a single measure of client satisfaction across all three agencies contracting for the waiver program.

Using the data collected from the various sources outlined in the methods section below, both formative and summative evaluations were conducted that focused on how well the program is being implemented, whether services are delivered as intended to the target population, and whether the program is cost effective. Six research questions guided the overall effort:

1. How many persons are receiving services through the Alzheimer's disease waiver program?
2. What are the characteristics of service recipients?

3. What are the characteristics of caregivers?
4. What are the types of services provided? Are they appropriate to the needs of the participants?
5. How satisfied are family caregivers with the program?
6. Is the program meeting the budget neutrality requirements of the 1915 (b) waiver, and has the program generated cost savings?

The evaluation was designed to make maximal use of existing databases as well as evaluation opportunities made possible by the waiver program itself. During FY 2005-06, the time period included in the analyses was extended from FY 2001-02 through FY 2003-04, the latest year the data was available. It should be noted that the original submission by AHCA to CMS included a baseline comparison year of 2001-2002. The independent contractor has submitted an analysis of two comparable groups of recipients with Alzheimer's disease for that base year (Chiriboga et al., 2005).

The study populations, summarized in Table 1, consisted of the following:

1. **All recipients who participate in the Alzheimer's disease waiver program (N=38)** as operated by the Miami-Dade and Broward County vendor, the Miami Jewish Home and Hospital for the Aged (MJHHA). Recipients from Palm Beach and Pinellas Counties were not included due to the low number of participants at these sites.

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 DOEA's 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 Alzheimer’s disease waiver program (N= 38)** as operated by the Miami-Dade and Broward County vendor.
3. **Medicaid waiver comparison group (N=90)** which consisted of Medicaid recipients participating in the 1915(b, c) Medicaid Aged/Disabled Waiver (A/DA) program; the latter is specified in the AHCA contract with CMS as the primary comparison group. The goal of the Aged/Disabled program, like that of the Alzheimer’s disease waiver program, is to “help individuals who are at risk of nursing home placement to remain at home or in a community setting” (DOEA (2004). For FY 2002-03, this waiver program served 12,537 adults aged 60 and over. Inclusionary criteria for the Aged/Disabled comparison group include:
 - Meet clinical criteria for being at risk of nursing home placement (CARES assessment)
 - Eligible to receive services under Medicaid (DCF financial assessment)
 - Age 60 and over (or disabled adults aged 18-59)
 - Unable to care for themselves without assistance

Note that Alzheimer’s disease is not specified as an inclusionary criterion for the Aged/Disabled waiver (A/DA) program. A/DA participants selected for inclusion in the evaluation project will consist of all those diagnosed with Alzheimer’s disease regardless of county of residence. During the recently completed assessment by the independent evaluation team (Chiriboga et al., 2005), 58 recipients in the A/DA program during FY 2001-02 met all study criteria. For the FY 2005-06 project, 90 A/DA participants from 2003-4 were identified and included.

Table 1
Study Populations

1. Alzheimer’s disease waiver beneficiaries	Approximately 38 beneficiaries diagnosed with Alzheimer’s disease who are participating in the Alzheimer’s disease waiver project
2. Caregivers for Alzheimer’s disease waiver beneficiaries	Approximately 38 caregivers of waiver beneficiaries
3. Aged/Disabled waiver beneficiaries (comparison group)	90 Medicaid beneficiaries who participated in the Aged/Disabled waiver program conducted in the State of Florida

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:

1. **State collected data.** Data from FY 2003-04 were used. Administrative datasets included CARES (Comprehensive Review and Evaluation Services; Department of Elder Affairs) and Medicaid. During the current year, the focus was on matching datasets for each client, preparing datasets, and cleaning datasets. These efforts will allow comparisons of the services provided to

members of the two samples. While administrative data on Alzheimer's disease Medicaid waiver recipients were not available to the evaluation team during the project year, the preparation of existing datasets provided templates for establishing the datasets for the Alzheimer's disease waiver program. Data provided by AHCA to the evaluation team consisted of cost records of the Alzheimer's waiver program for one vendor who had accrued a reasonably-sized complement of Medicaid recipients. These data included overall monthly costs since preliminary start-up in May 2005 as well as costs calculated for recipients from January 2006 through March 2006. This latter period was determined to represent an adequate reflection of actual per user costs.

- **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 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.** During the current project year, Medicaid data for FY 2003-04 were used in assessments of the Aged and Disabled Waiver (A/DA) comparison group. For the MAP recipients, data on paid claims were obtained directly from AHCA. The data, extracted by AHCA in early June of 2006, consisted of total claims paid for participation in the MAP, as well as totals for non-MAP Medicaid claims for the period extending from January through March 2006. That period was selected as being (1) the least likely to be affected by start-up fluctuations and yet (2) have a reasonable level of stability in terms of claims denied and claims pending.
2. **Provider-generated data.** As noted in the presentation of CARES data, the evaluation team collected data directly from records maintained by the Miami-Dade/Broward County provider. The data collection, which took place in early May 2006, 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 FY 2004-05, the evaluators 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 following measures:

- **Geriatric Depression Scale Short Form (GDS-SF).** A short 15-item version of the Sheikh & Yesavage 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.
- **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 (3 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.
 - **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, 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.
3. **Satisfaction Survey.** In addition to information collected by the vendor, AHCA staff worked collaboratively with the independent evaluators and the vendors to establish a client satisfaction instrument that could be used across all vendor sites. The instrument, translated into Spanish by the evaluation team, was designed to be used for a six-month and one-year satisfaction survey. For this study, the decision was made to mail a shorter satisfaction survey to those caregivers who had completed at least four months of program participation. Caregivers completed a series of questions about their own

experiences and satisfaction with MAP. The shorter version (see Appendix) was mailed to approximately 20 caregivers by the Miami-Dade/Broward County provider in late May 2006. Seven completed surveys were returned in self-addressed and postage-paid envelopes directly to the evaluator (an eighth was received on June 20th, too late to be included in the report; its contents were consistent with that of the other surveys).

During the May 2006 site visit made by members of the evaluation team, data were collected on patient care plans and matched with services provided. This process was facilitated by the fact that contract requirements stated that an “individual’s written plan of action” must be prepared by the vendor for each beneficiary and must specify services required. The contracting staff members were particularly helpful in providing the patient care plans and the CARES data for each recipient. The patient care plan allowed the evaluation team to evaluate whether the plan called for any of the specific services provided by MAP and whether such services were being provided. The specific services included:

- 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

In addition to the data collection activities, the evaluation team members interviewed the program coordinator, the program director, the medical director, and the four case managers assigned to MAP. One member of the team accompanied a case manager on a home visit to observe procedures.

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, with a number of changes in approach made as the delay in beneficiary enrollments became apparent. 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. Chi square and t-test 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/Discussion

Before addressing the specific questions and hypotheses, a brief historical overview of MAP is provided. The initial contract was approved in August 2004. A challenge to the initial approval of the contract to a provider for the Palm Beach area resulted in the necessity to re-bid the Palm Beach RFA. The contract for the Palm Beach area was not approved until the spring of 2006.

Over the past six to eight months, the Miami-Dade/Broward provider reported to the site team that they encountered problems with obtaining approval of subcontractors. In addition to delays in approval of subcontracting providers, a provider reimbursement issue surfaced in the fall of 2005 that complicated implementation timelines.

Question One: Number of Recipients Receiving Services

As mentioned earlier in this report, six questions were intended to guide the overall effort. The first of these was: “How many persons are receiving services through the Alzheimer’s disease waiver program?”

A review of files conducted during the site visit in early May indicated that at least 63 Medicaid beneficiaries had been enrolled by the MJHHA. Approval for six additional Medicaid beneficiaries was pending. In addition to the Medicaid recipients who had already been approved for enrollment in MAP, the MJHHA was actively engaged in the recruitment and processing of new clients. Table 2, copied by the evaluation team from an in-house client status report prepared by MJHHA staff at the end of March, indicated vigorous recruitment progress. A total of 73 potential participants were identified at the earliest stage of the process of enrollment, while the paperwork for 10 clients had been submitted to the Department of Child and Family Services, and four more clients were pending activation. In addition, the applications of 77 potential participants had been terminated, or disenrolled, since program start-up, and 29 clients had been approved and officially entered into MAP. Of these, seven were residents of Broward County, and 16 were from the Miami-Dade area. Since the time this report was prepared, and as indicated in an earlier table, several more participants have been enrolled. In addition, the vendors from Palm Beach and Pinellas Counties have commenced operations. As of June 2006 (per report from the AHCA contract manager for MAP, provided June 7, 2006), Palm Beach had approved five recipients and Pinellas had two approved recipients.

Table 2
March 30, 2006 list prepared by MJHHS of in-process client enrollments

Status	New MAP: Dade	New MAP: Broward	Transfers	Total Clients
Pending Application & PRF	44	14	15	73
PRF Received pending UCA	8	2	10	20
PRF problems	3	4	17	24
UCA completed pending CARES	1	0	3	4
Clients at CARES	2	1	8	11

Status	New MAP: Dade	New MAP: Broward	Transfers	Total Clients
Clients returned from CARES no level of Care assessment	2	0	2	4
Client returned from CARES pending Medicaid	3	1	9	13
Clients at DCF	4	1	5	10
Clients pending activation	0	0	4	4
Total Clients	67	23	73	163
Disenrolled	N/A	N/A	N/A	77
MAP Active	3	3	7-Broward 16-Dade	29

Question Two: Recipient characteristics

The second question was “What are the characteristics of service recipients?” To obtain an answer to this question, the evaluation team analyzed data from two sources. The first source consisted of data obtained during the May 4 visit to MJHHA by two members of the evaluation team. These data included information from CARES. The second data source consisted of intake forms that had been completed for Medicaid recipients and their caregivers in the first and second months after enrollment. It should be noted that the number of Medicaid recipients included in assessments differed due to differences in the source and availability of information.

Medicaid recipients: Data from CARES. Data were available for 31 to 33 recipients, depending on the particular item. As Table 3 shows, the average age of the participants was slightly over 79. The age range was 65-92. Given the relatively advanced age of the recipients, the fact that nearly three quarters of the Medicaid recipients were women is not surprising. The majority of recipients were either African American (12%) or Hispanic American (67%), reflecting the demographics of the geographic location of the MJHHA. The MJHHA catchment area includes two counties with high proportions of African American and Hispanic American residents. Because of the high proportion of Hispanic Americans, and the fact that for nearly two-thirds of the recipients Spanish was their primary language, it is noteworthy that all case workers at MJHHA are bilingual and that materials for MJHHA’s MAP are printed in both languages.

Table 3
Characteristics of Medicaid recipients enrolled in MAP

Beneficiary Attribute	N (valid %) or Mean (SD)
Average Age	79.23 (7.72)
Female	24 (72.7)
African American	4 (12.1)
Hispanic American	22 (66.7)
Spanish as primary language	20 (62.5)
Married	15 (45.5)
Monthly income \$500 or under	3 (15.8)
CARES answered by proxy	26 (65.0)

From a social resources point of view, it is clear that the recipients were not socially isolated. All of the recipients had a caregiver and more than 45% were married. However, the recipients were found to be financially vulnerable. All recipients met the fiscal criterion for enrollment in MAP, and three had monthly incomes of less than \$500. As a final comment on Table 3, the general capacity of the recipients to function independently was suggested by the fact that in two-thirds of the cases, most of the information on the CARES assessment tool was provided by the caregiver rather than directly by the beneficiary.

Table 4 presents CARES data on psychological and physical well-being. CARES data represent ratings and judgments as indicated by trained health professionals. The general impression is one of an at-risk and frail population. Life satisfaction was reported to be relatively low. On a four-point scale, only 8 out of 32 (21.9%) were reported to have “good to excellent” life satisfaction, while 9 (28%) reported low levels of life satisfaction. All recipients were perceived as needing supervision, and nearly 40% exhibited wandering behavior. Over 90% were said to demonstrate significant memory problems, nearly 80% had no correct responses on the abbreviated cognitive inventory included in CARES, and nearly all were reported to have cognitive problems. Abusive or disruptive behavior was also reported in slightly less than half the cases.

On the positive side, very few beneficiaries were reported to be lonely or to have thoughts of suicide. This would be expected in a group of recipients all of whom lived with a caregiver. The fact that one-third of the recipients did not have formal or informal supports always available demonstrates that simply living with a caregiver may not always provide for all of one’s needs. The need for a mental health referral was identified for just one of the recipients, which may explain the relatively minimal use of this service in the care plans that will be described later in this report. For more than one-third of the recipients, overall health was reported to be “good to excellent.” This reinforces a basic point about Alzheimer’s disease: it is not necessarily associated with declines in physical health. Indeed, with good care, the individual’s health may remain reasonable for substantial periods of time. The fact that one-third of the recipients were in good health may also be an indication of quality care on the part of the caregivers.

Table 4
Beneficiary Information on Psychological
and Physical Conditions Abstracted from CARES

Satisfaction with life "good to excellent"	8 (21.9)
Satisfaction with life "poor"	9 (28.1)
Behavior indicates need for supervision	32 (100.0)
Wanders for no apparent reason	13 (39.4)
Demonstrates significant memory problems	31 (93.9)
Oriented to time	6 (18.2)
Oriented to place	10 (30.3)
Appears depressed	8 (24.2)
Appears to be lonely or dangerously isolated	2 (6.1)
Has thoughts of suicide	2 (6.1)
Abusive, aggressive or disruptive behavior	15 (46.9)
Presents other problems	13 (44.8)
Ten (maximum) errors in cognition	26 (78.8)
Cognitive problems are present	30 (96.8)
Currently receiving mental health services	11 (37.9)
Need for mental health referral indicated	1 (3.2)
Formal/informal services always available	22 (66.7)
Overall health good to excellent	10 (31.3)

Medicaid recipients: Data from intake forms. Data were available for 38 recipients. The intake form was administered by the case manager during the first home visit and consisted primarily of a modified Mini-Mental Status Exam, the 3MS, and a series of questions dealing with the recipients' quality of life. While the modified 3MS was administered directly to the beneficiary, a total of 36 (92.3%) of the quality of life questions were answered by the caregiver. In other words, nearly all the available information on quality of life was provided by someone other than the beneficiary.

As shown in Table 5, more than 50% of the Medicaid recipients were unable to provide even one correct response to questions on the 3MS. All recipients fell below the cutoff point for serious cognitive deficit of 77/78. There is therefore evidence that all of the Medicaid recipients enrolled in MAP were seriously compromised with respect to cognitive functioning.

Table 5
Modified MMSE total score for recipients

Modified MMSE Score	Frequency	Valid Percent
0	20	52.6
4	1	2.6
7	1	2.6
9	2	5.3
12	1	2.6
13	1	2.6
22	1	2.6
24	1	2.6
29	1	2.6
31	1	2.6
39	1	2.6
40	1	2.6
41	1	2.6
47	1	2.6
51	1	2.6
53	1	2.6
60	1	2.6
61	1	2.6
Total	38	100.0

In addition to the test of cognitive capacity, a series of questions was asked about the recipients' psychological well-being using the 15-item short form of the GDS (Table 6). For the GDS and remaining items focused on the Medicaid beneficiary, the caregiver provided the response in all but two instances. For this reason the results should be interpreted with caution. As can be seen from Table 6, the caregivers tended to provide a picture of the recipients that was generally quite positive. Positive items on the 15-item GDS, for example, were overwhelmingly endorsed, while negative items were attributed to individuals in only a few cases by caregivers.

Table 6
Beneficiary or proxy responses to the GDS-SF measure of depressive symptoms.

Item	N (and Valid Percent) Endorsing	N (Percent) Missing
Basically satisfied with life	16 (94.1)	21 (53.8)
Dropped many activities	9 (52.9)	21 (53.8)
Feels life is empty	7 (41.2)	21 (53.8)
Often feels bored	6 (35.3)	21 (53.8)
Mostly in good spirits	15 (93.8)	22 (56.4)
Afraid something bad will happen	2 (12.5)	22 (56.4)
Feels happy most of the time	16 (94.1)	22 (56.4)
Often feels helpless	3 (18.8)	22 (56.4)

Item	N (and Valid Percent) Endorsing	N (Percent) Missing
Prefers to stay at home	9 (52.9)	21 (53.8)
Has more problems with memory than most	6 (35.3)	21 (53.8)
Feels its wonderful to be alive	15 (93.8)	22 (56.4)
Feels pretty worthless the way things are	5 (33.3)	23 (59.0)
Feels full of energy	13 (81.3)	22 (56.4)
Feels situation is hopeless	6 (40.0)	23 (59.0)
Feels others are better off	6 (40.0)	23 (59.0)

The distribution of overall summary scores for the GDS-SF is shown in Table 7. More than 70% of the Medicaid recipients fell below the cutoff point of 5; therefore, they had a relatively low probability of being diagnosed with depression if they were to be seen by a clinical psychologist or psychiatrist. Only five of the 17 recipients with ratings had a score indicative of depression. These results suggest that the quality of life for the majority of recipients was reasonably good, although again it must be noted that it was the caregiver who furnished the rating.

Table 7
Total summary scores for the GDS-SF

GDS-SF Score	Frequency	Valid Percent	Cumulative Percent
.00	1	5.9	5.9
1.00	4	23.5	29.4
2.00	3	17.6	47.1
3.00	1	5.9	52.9
4.00	2	11.8	64.7
5.00	1	5.9	70.6
6.00	3	17.6	88.2
8.00	1	5.9	94.1
14.00	1	5.9	100.0
Total	17	100.0	

ADL scores obtained by the case managers revealed that the majority of MAP recipients had multiple dependencies (Table 8). Scores were available for 36 of the 38 Medicaid recipients. Of these, well over 70% were judged to be dependent on each ADL area. Approximately 87% were unable to dress themselves, for example, and 86% were unable to bathe themselves. Over three-quarters of the sample were unable to go to the bathroom alone or were incontinent. Both of these latter ADLS are highly related to risk of institutionalization because family members often find it difficult to assist in these activities.

Table 8
Dependency in Activities of Daily Life
among Medicaid recipients enrolled in MAP
(N=36)

ADL Item	Number (Valid Percent) Dependent
Bathing	31 (86.1)
Dressing	34 (87.2)
Toileting	30 (76.9)
Transferring	26 (72.2)
Continence	28 (77.8)
Feeding	27 (75.0)

Because ADLs have a cumulative impact on independence, the evaluators also looked at the total number of dependencies per beneficiary. The data reported in Table 9 indicate that 21 recipients—well over half—were judged to be dependent on all six ADLs. In only one instance was a beneficiary rated as having a single dependency. Nearly 84% were dependent on three or more activities, thus meeting a criterion often used as part of the evaluation for services or institutionalization. These results, coupled with the results obtained with the modified MMSE, demonstrated that the Medicaid recipients selected for participation in MAP met the selection criteria. Their depth of dependency clearly would impose a substantial burden on caregivers.

Table 9
Count of dependencies in ADLs among Medicaid recipients (N=37)

Dependency Count	Frequency	Valid Percent	Cumulative Percent
.00	1	2.7	2.7
1.00	1	2.7	5.4
2.00	4	10.8	16.2
3.00	4	10.8	27.0
4.00	1	2.7	29.7
5.00	5	13.5	43.2
6.00	21	56.8	100.0

On Instrumental Activities of Daily Life, MAP recipients were reported to be more dependent than was evidenced by their ADL scores. As shown in Table 10, between 75% and 97% of the MAP recipients were completely unable to perform specific IADLs. For example, 97% were unable to prepare meals, do housework and handiwork, or do laundry. These figures add another dimension to the ADL dependencies reviewed above. Not only were the recipients largely unable to do basic tasks, but the majority were also unable to manage living alone in any sense.

Table 10
MAP Medicaid recipients completely dependent
on Instrumental Activities of Daily Life, or independent in performing activities (N=36)

	Number (Valid Percents)	
	Unable to do	Needs no help
Using the telephone	27 (75.9)	3 (8.3)
Transportation beyond walking distance	30 (83.3)	3 (8.3)
Grocery shopping	34 (94.4)	0 (0.0)
Meal preparation	35 (97.4)	0 (0.0)
Housework and/or handyman work	35 (97.2)	0 (0.0)
Doing laundry	35 (97.2)	0 (0.0)
Taking medications	29 (80.6)	0 (0.0)
Managing money	34 (94.4)	1 (2.8)

The cumulative load of IADL dependencies is shown in Table 11. Over two-thirds of the total number (n = 24) were unable to conduct any of the eight IADLs. Only one was able to perform all eight activities with some assistance (Table 12).

Table 11
Count of recipients with total dependency on IADLs for Medicaid recipients (N=37)

Valid	Frequency	Valid Percent	Cumulative Percent
.00	1	2.8	2.8
4.00	1	2.8	5.6
5.00	1	2.8	8.3
6.00	5	13.9	22.2
7.00	4	11.1	33.3
8.00	24	66.7	100.0

Question Three: Characteristics of Caregivers

The third research question was “What are the characteristics of the caregivers?” Two data sources were used to obtain an answer to this question. Both sources consisted of data obtained during the May 4 visit to MJHHA by two members of the evaluation team. These data included (1) information from CARES and (2) information from the intake forms that had been completed by the caregivers to Medicaid recipients in the first and second months after enrollment. It should be noted that the number of caregivers included in assessments differed from source to source due to differences in the source of information.

Caregiver characteristics: CARES data. Data were available from 30 to 33 caregivers, depending on which question was being addressed. Table 12 provides a summary of the characteristics of caregivers. Approximately 57% of the caregivers reported they were an adult child (57.6%) of the Medicaid enrollee, and 42.4% reported they were a spouse. Approximately two-thirds were women. Slightly

less than half of the respondents reported being in fair to poor health. This latter statistic is important because caregivers who are in fair to poor health may have problems providing the level of care required by individuals with Alzheimer’s disease. However, at the time of the CARES assessment, approximately 94% of caregivers reported that it was very likely that they would continue providing care, and 94% felt that they would be capable of providing care. The health professional completing the form seemed to agree, rating approximately 94% as very likely to be able to provide care.

Table 12
Characteristics of caregivers, as derived from the CARES data obtained from MJHHA

CARES item	Frequency (%)
Caregiver is spouse	14 (42.4)
Caregiver is child	19 (57.6)
Caregiver is female	22 (66.7)
Caregiver’s health is fair to poor	15 (45.4)
Caregiver provision for over two years	26 (86.7)
Very likely caregiver will continue care provision	30 (93.8)
Caregiver feels “very likely” to be able to provide care	31 (93.9)
Assessor’s rating of caregiver ability as “very likely”	28 (93.3)

Caregivers to Medicaid recipients: Data from intake forms. Month One intake data were available for all 38 caregivers. Looking first at responses to the 15-item Geriatric Depression Scale, the results provide a mixed message (Table 13). Nearly three-quarters of the caregivers reported they felt satisfied with life, and 84% reported feeling it was wonderful to be alive. On the other hand, approximately 79% reported having dropped many activities, 47% were afraid something bad would happen, 45% often felt helpless, and over a quarter felt they were in a hopeless situation. These responses may suggest that while caregivers were basically healthy from a mental health perspective, they were in an emotionally draining situation.

Table 13
Item Endorsements By Caregivers
for the 15-item Version of the Geriatric Depression Scale (GDS-SF)

Item	N (and Valid Percent) Endorsing
Satisfied with life	28 (73.7)
Dropped many activities	30 (78.9)
Feels life is empty	14 (36.8)
Often feels bored	15 (39.5)
Mostly in good spirits	31 (81.6)
Afraid something bad will happen	18 (47.4)
Feels happy most of the time	24 (63.2)
Often feels helpless	17 (44.7)
Prefers to stay at home	12 (31.6)
Has more problems with memory than most	12 (31.6)

Item	N (and Valid Percent) Endorsing
Feels its wonderful to be alive	32 (84.2)
Feels pretty worthless the way things are	6 (15.8)
Feels full of energy	19 (50.0)
Feels situation is hopeless	10 (26.3)
Feels others are better off	6 (15.8)

Responses to the 15 individual items on the GDS-SF present a mixed impression on the overall psychological well-being of the caregivers (Table 14). The summary GDS-SF scores, on the other hand, show that approximately one-third of the caregivers had scores of six or above, suggesting the possible presence of a depressive disorder. The greater proportion of caregivers manifesting depressive symptoms, in contrast to their care recipients, is not unusual (e.g., Chiriboga, 2006; Kane, Ouslander & Abrass, 2004). What is important for the purpose of this report is the evidence of emotional vulnerability suggested by these scores. At least a third of the caregivers reported they were emotionally vulnerable prior to participation in MAP.

Table 14
GDS-SF Frequencies for Caregivers

Summary Score	Frequency	Valid Percent	Cumulative Percent
.00	2	5.3	5.3
1.00	6	15.8	21.1
2.00	3	7.9	28.9
3.00	4	10.5	39.5
4.00	4	10.5	50.0
5.00	4	10.5	60.5
6.00	2	5.3	65.8
7.00	3	7.9	73.7
9.00	4	10.5	84.2
10.00	2	5.3	89.5
11.00	2	5.3	94.7
12.00	1	2.6	97.4
13.00	1	2.6	100.0
Total	38	100.0	

Caregiver scores on the Geriatric Depression Scale suggest that caregivers may be facing a situation accompanied by multiple signs and symptoms of depression, even though they had strong emotional resources as well. A more direct way of considering the impact of caregiving is through assessment of caregiver burden (Table 15). Responses to a brief, 12-item burden scale suggested that the caregiver experience had been mixed but it was a definite strain. Over half of the caregivers reported stress arising from conflicting responsibilities, over 47% felt they had insufficient time for themselves, about 45% said their social life had suffered, and nearly 40% felt their health had suffered. On the other hand, only 18% felt that

their relative had affected their relationship with others; 21% reported they felt they had lost control over their life. These results are consistent with the extensive literature on caregiver burden (e.g., Molinari, 2006).

Table 15
Caregiver responses to burden scale items

Burden Attribute	N (and valid %) reporting feeling quite often to nearly always
Not enough time for self	18 (47.4)
Stress between competing responsibilities	21 (55.3)
Feels angry when around relative	14 (36.8)
Not enough privacy	09 (24.3)
Feels strained around relative	09 (23.7)
Feels has lost control over life	08 (21.0)
Relative affects relationship with others	07 (18.4)
Social life has suffered	17 (44.7)
Health has suffered	15 (39.5)
Uncertain what to do	09 (23.7)
Feels should be doing more	12 (32.4)
Feels could do a better job	11 (29.0)
Number with no "never" responses	10 (25.6)
Number with six or more "always" responses	03 (7.8)

Another way of looking at the burden data is to consider how many respondents provided an extreme score. Here the evaluators considered how many of the caregivers, at the point where they had not yet received any services from MAP, said that they never experienced any of the 12 components of burden captured by the burden scale. A total of ten, slightly over a quarter of the caregivers, reported that they had never felt burden in any of the 12. On the other hand, three caregivers (approximately 8%) reported that they "always" felt burdened in six or more of the components.

One factor that may be associated with burden is the health of the caregiver. On the ADL instrument, 39 caregivers rated themselves on ADLs (Table 16). From 1 (2.6%) to 4 (10.3%) of the caregivers reported dependencies, with the most (N=10) being dependent on assistance for bathing. One caregiver appeared to be in substantial need, reporting being dependent on all six ADLs assessed. Another three were dependent on up to three. However, on the whole, the caregivers were not dependent; 34 rated themselves as independent on all six items.

Table 16
Dependency in Activities of Daily Life
Among Caregivers to Medicaid Recipients Enrolled in the MAP
(N=39)

ADL Dependency Item	Number (%) Dependent
Bathing	4 (10.3)
Dressing	3 (7.7)
Toileting	3 (7.7)
Transferring	1 (2.6)
Continence	3 (7.7)
Feeding	1 (2.6)
Number dependent on all ADLs	1 (2.6)
Number dependent on 3 or more ADLS	3 (7.7)

On instrumental activities of daily life (IADLs), one caregiver was dependent on all eight IADLs, but the proportion that reported needing no help was substantial: from approximately 72% (house- or handyman work) to over 92% (use of telephone, taking medications). Indeed, 27 (69%) of the 39 were independent on all IADLs (Table 17).

Table 17
Caregivers to MAP Recipients
Who Were Either Unable to do Instrumental Activities
of Daily Life, or Completely Able
(N=39)

	Number (%)	
	Unable to do	Needs no help
Using the telephone	1 (2.6)	36 (92.3)
Transportation beyond walking distance	1 (2.6)	32 (82.1)
Grocery shopping	1 (2.6)	32 (82.1)
Meal preparation	1 (2.6)	32 (82.1)
Housework and/or handyman work	1 (2.6)	28 (71.8)
Doing laundry	1 (2.6)	32 (82.1)
Taking medications	1 (2.6)	36 (92.3)
Managing money	1 (2.6)	32 (82.1)
Number dependent on all IADLs	1 (2.6)	
Number independent on all IADLs	27 (69.2)	

Question Four: Services Provided

The fourth question was “What are the types of services provided? Are they appropriate to the needs of the participants?” Care plans and services provided were reviewed for 29 recipients. Other recipients had only recently been approved and their information was incomplete. In addition to the review of care plans and services, one member of the evaluation team accompanied a case manager on a home visit to obtain additional data.

Comprehensive care plans had been prepared for all 29 recipients whose charts were reviewed (Table 18). The earliest care plan had been completed on October 31, 2005, while the most recent had been completed on May 4, 2006 (the date the data were collected). The care plans had been updated on a monthly basis. The plans detailed service needs (or the lack of need) related to each service area covered by the waiver, as well as indications of other needs and how they should be addressed. Dates of implementation of services in response to the care plan were also provided, and the dates indicated that service provision was begun promptly. The services were all appropriate to the needs of the Medicaid beneficiary and/or caregiver. From the data available, it was not immediately clear why few environmental modifications, pharmacy reviews, behavioral assessments, wanderer alarm systems and wanderer identification services had been ordered. However, interviews with staff indicated that the reason was a combination of the comparatively recent program start-up and a prioritization of client needs.

Table 18
Services Included in Care Plans
of 29 Medicaid Recipients in MAP

Service included in care plan?	N (%) Yes
Adult Day Health	22 (71.0)
Respite Care	20 (64.5)
Behavioral Assessment	0 (100.0)
Caregiver Training	26 (83.9)
Environmental Modification	1 (2.5)
Incontinence Supplies	21 (70.0)
Personal Care	23 (74.2)
Pharmacy Review	1 (3.3)
Wanderer Alarm System	2 (6.5)
Wanderer Identification	3 (9.7)

It is important to recognize that the ultimate test of whether or not the services are appropriate to the needs of participants should be drawn from an evaluation of the extent to which MAP leads to an increase in time spent in the community. As of June 2006, two MAP recipients had been admitted to an assisted living facility. This constitutes approximately 3% of approved recipients. Another 3% had died.

Question Five: Client Satisfaction

The fifth question asked was “How satisfied are family caregivers with the program?” A survey was sent by MJHHA to approximately 20 caregivers in May 2006. As of the date this report was revised (August 2, 2006), 11 surveys had been returned. The average age of the respondents was 61.45, with a standard deviation of 11.9. The average age was heavily influenced by one 36-year-old caregiver; the remainder were aged 51 to 78 (average = 64.0). The gender distribution approximates that found in other studies of caregivers to persons with Alzheimer’s disease (i.e., Chiriboga, Yee & Weiler, 1992): four men (36%) and seven women (64%). Three of the caregivers were spouses and eight were children, again a proportion that approximates that found in other studies.

The survey questions dealt with how the services being received were helpful to the caregivers themselves. Because of the small number of responses, the results should be taken as only suggestive. In response to a question about the most helpful service or services, nine of the eleven (82%) reported that the personal care assistant was either the most helpful or the second most helpful, while seven (64%) mentioned adult day care and two (18%) reported respite care as first or second most helpful. No respondent rated any of the services as “least helpful.” When asked if there were services that they were not receiving that would be helpful, seven caregivers (64%) reported that it would be very helpful if the personal care assistant could work additional hours or at night or on weekends. This same point—a need for more hours and more flexibility in days of provision—was mentioned by the caregiver during a home visit attended by a member of the evaluation team.

Nearly all caregivers were satisfied with MAP services. Ten of the eleven (91%) were either somewhat or very satisfied with the services. One caregiver was very dissatisfied. However, this same individual also reported that the services improved quality of life “a lot,” so it may be that the caregiver had circled the wrong response.

Another question in the survey dealt with whether respondents felt that “the services provided to you or your loved one improved your quality of life?” There were no responses indicating that the services did not improve quality of life. Four (36%) felt that their quality of life was improved “a little,” while seven (64%) reported that the services improved their quality of life “a lot.”

A final survey question asked whether “the MAP services are helping you maintain the enrollee at home rather than a nursing home?” Similar to the response for quality of life, two (18%) caregivers said “Yes, but not for long” and nine (82%) said that the services would help them maintain the enrollee at home for the foreseeable future.

In summary, family caregiver satisfaction is integral to the success of MAP itself because the overarching intent of MAP is to provide services that will allow caregivers to maintain Medicaid beneficiaries with Alzheimer’s disease in their homes for longer periods of time. Early results indicate that the caregivers were indeed satisfied with the program. Only two of the eleven caregivers responding

to the survey stated that while the MAP services were helping to maintain the enrollee at home, it would not be for long. The available data do not suggest what might be done to assist those who are contemplating institutionalization. However, several of those responding to the survey, including one of the two contemplating institutionalization in the near future, reported the need for either more time or more flexible hours on the part of personal care assistants.

Question Six: Budget Neutrality

The sixth and final question was “Is the program meeting the budget neutrality requirements of the 1915 (b) waiver, and has the program generated cost savings?” Stabilized data on paid claims for services provided to substantial numbers of the existing MAP participants were not available from the administrative database. As an alternative, data on paid claims were made available directly by AHCA. The comparison group consisted of Medicaid recipients with Alzheimer’s disease who participated in the Aged and Disabled Waiver (ADW) Program SFY 2003-04. For the ADW group, CARES/CIRTS data were used to identify recipients who either (1) had a caregiver who did not live with the beneficiary, (2) had a caregiver who lived with the beneficiary, or (3) did not have a caregiver either living with them or at another residence, or there was no information available on caregiver presence or absence.

Table 19 presents data on total costs, number of participants, and per user per month (PUPM) dollar costs. For the ADW group, PUPM was computed on the basis of paid claims for the entire SFY 2003-04. Data for the entire year were used in order to lend stability to the PUPM estimates. However, for the PUPM estimates for MAP, only paid claims cost data for the first three months of calendar year 2006 were used: January, February, and March. At the point where data were provided, in late May, the first three months of 2006 provided the most recent period for which it (1) could be assumed that no major increases or decreases, due to denial of claims or late approval of claims, might affect costs, and (2) there were sufficient participants to allow some stability of results. It should be noted that Table 19 includes, for A/DA recipients, PUPM costs for recipients broken out into costs for those with caregivers, caregiver residents with beneficiary, or no caregivers. Since the overall program costs for MAP are only for the group with caregiver residents with beneficiary, the overall costs are the same as those for the single MAP group.

The results provide evidence that the costs of MAP are significantly less than those associated with the Aged and Disabled Waiver (ADW) Program. This is true for the costs specific to the two programs and for total Medicaid costs, exclusive of program-specific costs. When only those with a live-in caregiver were compared, the PUPM program costs for MAP were \$342 less than ADW, and the remaining Medicaid costs were \$729 less. As an aside, it was of interest that the PUPM program costs for ADW recipients were substantially less if the enrollee had a caregiver living apart than if the caregiver lived with the enrollee. The latter recipients had the highest PUPM both for program costs and for Medicaid costs

exclusive of ADW program costs. The reason for the differences may be that caregivers are more likely to live with the Medicaid beneficiary if the latter has a higher need for help and services.

Table 19
Per user per month (PUPM) costs associated with the Medicaid recipients participating in the Aged and Disabled Waiver Program and the Medicaid Alzheimer's program.

	Aged and Disabled Program			Medicaid Alzheimer's Program		
	Total Cost	N clients	PUPM	Total Cost	N clients	PUPM
Program Costs	\$1,185,843.16	90	\$1,098.00***	\$60,925.42	26	\$781.10
Caregiver	\$49,880.58	5	\$831.34	NA	NA	NA
Living w/Caregiver	\$1,023,833.39	76	\$1,122.62***	\$60,925.42	26	\$781.10
No Caregiver	\$112,129.19	9	\$1,038.23	NA	NA	NA
Total Medicaid Costs	\$1,757,313.27	90	\$1,627.14***	\$73,210.82	26	\$938.60
Caregiver	\$69,241.15	5	\$1,154.02	NA	NA	NA
Living w/Caregiver	\$1,520,997.61	76	\$1,667.76***	\$73,210.82	26	\$938.60
No Caregiver	\$167,074.51	9	\$1,546.99	NA	NA	NA

***T-test probability < .001

Table 19 also shows that when the costs of all ADW recipients were compared with the costs of MAP, the latter again was substantially lower in program and overall Medicaid costs. These results, and those for the comparisons for only those with a live-in caregiver, should be interpreted with caution because (1) only data for a three-month period were used to compute PUPM for the MAP participants, (2) the program itself was in an early roll-out stage, and (3) the MAP data on paid claims may be unstable because claims may be in a pending status for months, and the level and future status of pending claims for the MAP is unknown. It is usually recommended that claims data be carried forward for at least six months, if not an entire year, in order to ensure that the data are in final form.

In summary, the results from the present investigation, while only preliminary in nature, support the assumption that the overall program is budget-neutral. Based on the preliminary PUPM data on paid claims for the period extending from January through March of 2006, it was found that the MAP program cost significantly less than the ADW program designated as a comparison sample in the original waiver application to CMS. In comparison to the costs that would be incurred if the program did not exist and the recipients were institutionalized, the preliminary results indicate that MAP has the potential to be cost-effective. Based on the current PUPM calculations, the combined cost of MAP plus all other Medicaid expenses would be approximately \$20,636. This is approximately one-third of the current estimates of nursing home costs. Caution must be raised, however, because of the small size of the sample and because the program is still in its early stages.

Discussion

The results of the evaluation conducted by the independent evaluators indicate that the Medicaid recipients currently participating in MAP can be characterized as manifesting marked cognitive decline, behavioral problems, and a need for supervision. Their caregivers appear to be committed individuals who had provided quality care for substantial periods of time prior to program participation. The value of MAP was demonstrated by the data indicating that the caregivers, while committed, were frail and heavily burdened by the demands placed upon them. Given the presenting profile of beneficiary and caregiver needs, the multiple services offered through MAP are extremely well-targeted.

The efficacy of the services cannot yet be stated conclusively because it may take some time before services can have a sustained impact on recipients and caregivers. Caregiver training, for example, is not something that can be accomplished in one or two sessions. Similarly, the data suggest that both case managers and caregivers need to continue to identify ways to effectively coordinate services. Some concern was noted by the caregiver response to the satisfaction survey that the amount of time and schedule of personal care assistants might need to be reconsidered and adjusted to provide more hours and more flexibility in days of service provision. This was the single area in which those responding to the survey mentioned an unmet need.

The impact of the program on the well-being of recipients and their caregivers and the ability of MAP to help recipients remain in the community will take time to determine. One of the keys to program efficacy will be how well MAP providers are able to adjust services to the changing nature of the needs of recipients and their caregivers as Alzheimer's disease progresses. The evaluation team's assessment of care plans and services related to those plans suggests that MJHHA case managers were tracking changes and changing care plans in response to client needs. However, it was not yet possible to determine the efficacy of case management practices on the basis of the limited sample size and the limited time in which recipients have been enrolled in a fully implemented program.

From a fiscal perspective, MAP compared quite favorably to the monthly costs incurred by Medicaid recipients with Alzheimer's disease who were participating in the longstanding and much larger Aged and Disabled Waiver Program. The MAP costs were also substantially less, when extrapolated to a 12-month period, than those that would be incurred if the Medicaid recipients were to be placed in a nursing facility. However, these data must be considered preliminary because of the relatively recent implementation of the program.

While the evaluators have repeatedly cautioned that the results were based on a small sample of participants in a program that was still in the process of achieving full implementation, the preliminary results are quite encouraging. Overall, the activities reviewed in depth seem to suggest that MAP is having a positive effect on recipients and their caregivers.

Recommendations and Policy Implications

The early implementation of MAP suggests that it holds promise for providing services to individuals with Alzheimer's disease and their caregivers. It is recommended that these preliminary findings be verified in future studies. In addition, it is recommended that the long-term outcomes of MAP be assessed over time.

While most caregivers reported they were satisfied with life, many caregivers reported they were heavily burdened by the demands of the caregiver role. Over a third of the caregivers had scores indicative of possible depression during the period when they and their family member were enrolled in MAP. This finding suggests that, in addition to caregiver training, caregivers may be in need of services to handle the stresses and strains faced on a daily basis. It is suggested that consideration be given to adding mental health services for caregivers as an additional service.

The results, if substantiated over the next few years when more enrollees are participating, also raise the question of whether the guidelines for participation in the MAP should be broadened to include individuals currently in a long-term care facility. Aside from the goal of reducing fiscal costs associated with housing recipients with Alzheimer's disease in long-term care facilities, there are several reasons to consider alternative living arrangements. The current system of funding to take care of dependent elders was developed over 40 years ago, with the creation of Medicare and Medicaid, during a time when the available options for long-term caring were sparse. Generally, the options were family care or expensive nursing home care. Recognizing a need, the federal government legislated funding for nursing home care. In the 21st Century, multiple alternatives exist. Much of the growth of these alternatives is owed to actions of the disability movement, where consumer empowerment as a concept has flourished. Several states, including Vermont, New Jersey, Georgia, Texas and Florida have multiple approaches designed to accommodate home care. States may provide funding for family members to take care of loved ones, or provide transportation services. These represent alternatives to what Fredda Vladeck, director of the Aging In Place Initiative of the non-profit United Hospital Fund, has called "tired old templates" for long-term care (Wall Street Journal, 2006).

Another recommendation therefore is to review the feasibility of taking Medicaid recipients with any form of dementia out of institutional programs and moving them back into the community if they and their families are willing and if their levels of need are compatible with home or community placement. A policy of community reintegration for persons with dementia would be commensurate with the Olmstead Act and is made possible by the existence of programs such as Florida's Medicaid Alzheimer's Program.

It is also recommended that AHCA review current provider enrollment procedures and the approval of Medicaid recipients for participation in the Alzheimer's disease waiver program to ensure timely access to the program.

Finally, it is suggested that programs such as the Alzheimer's disease Medicaid waiver be extended to recipients with all forms of dementia. While Alzheimer's disease is the most prevalent form of dementia, it is not the only disorder that is associated with family burden. A related recommendation is the possibility of taking Medicaid recipients with any form of dementia out of institutional programs and moving them back into the community – if they and their families are willing and if their levels of need are compatible with home or community placement. A policy of community reintegration for persons with dementia would be commensurate with the Olmstead Act, and is made possible by the existence of programs such as Florida's Medicaid Alzheimer's Program.

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