

COST OF CARE:

QUANTIFYING CARE-CENTERED PROVISIONS OF THE 'NATIONAL PLAN TO ADDRESS ALZHEIMER'S DISEASE'

A REPORT BY THE ALZHEIMER'S FOUNDATION OF AMERICA

> EXECUTIVE SUMMARY

As our nation faces an escalating incidence of Alzheimer's disease,¹ there is no doubt that we must aggressively pursue efforts to both cure or effectively treat this disease, and to provide optimal support services to individuals with the brain disorder and their families. This reality frames the historic "National Plan to Address Alzheimer's Disease" (the National Plan),² released in May 2012 by the U.S. Department of Health and Human Services (HHS) and updated annually. The objectives laid out in the National Plan are laudable. Now is the time to bring them to life.

In an attempt to advance some of the goals in the National Plan, the Alzheimer's Foundation of America (AFA) undertook a project to quantify several of the plan's caregiver provisions and develop a cost-benefit analysis of their implementation. While the National Plan tasks government agencies with evaluating the system-wide applicability of proposals and strategies, AFA's goal is to take the initiative a step further by evaluating the costs and benefits associated with a full-scale implementation of these worthwhile provisions. This analysis is vital to ensure that the plan—a living document designed to be updated annually—is fully implemented to the benefit of the dementia population, their families and society.

AFA prioritized selected provisions in the National Plan, provided substance to the provisions, and developed methodology to implement the proposals in a low-cost or budget-neutral fashion. The goal of the AFA-selected provisions is to create a foundation upon which broad adoption of the National Plan may proceed. Implementing AFA-selected proposals as new or expanded demonstration projects will provide quantifiable examples of how changes in the delivery of services will result in overall cost savings. **If adopted, these approaches could result in more than \$110 billion in federal savings over 10 years** (See Appendix, Table 2).

The analysis is predicated upon suggested descriptions and cost estimates of the AFA-selected action steps in the plan that impact care delivery for people with Alzheimer's disease and their family caregivers. AFA proposed suggested details and specifications to the strategies, and contracted with respected health care economists to model these provisions and provide an overall cost analysis (See Appendix, Contributors).

Through limited implementation, the medical and caregiving community will demonstrate the benefits derived from redirecting services through these policy changes. At the same time, the analysis indicates that the selected provisions would only modestly increase budget outlays, by less than \$10 million over the 10-year budget period (See Appendix, Table 1).

¹ For the purposes of this paper, Alzheimer's disease refers to Alzheimer's disease and related dementias. Related dementias include frontotemporal, Lewy body, mixed, and vascular dementia. This collective definition of Alzheimer's disease is consistent with the approach both Congress and the U.S. Department of Health and Human Services (HHS) use in the *National Alzheimer's Project Act* (see footnote 2).

² The *National Alzheimer's Project Act* (Public Law 111-375), passed unanimously by Congress in December 2010, calls for establishing a National Plan for Alzheimer's Disease with input from a public-private Advisory Council on Alzheimer's Research, Care and Services. The first National Plan, issued in May 2012, can be found at: <http://aspe.hhs.gov/daltcp/napa/NatPlan.shtml>.

Further, although it does not identify specific cost savings for each of the AFA-selected provisions, the analysis suggests that other intangible benefits will result from each of them.

Cost savings aside, it is important to note that AFA's overarching intent in advancing these proposals is to improve the delivery and quality of care for people with Alzheimer's disease and improve the quality of life for their family caregivers—now and in the future as more and more people enter this fold. The analysis demonstrates that implementation of coordinated care delivery models, transitional care programs, and expanded caregiver supports will provide significant cost savings while promoting better health outcomes for individuals with Alzheimer's disease and improving quality of life for their caregivers.

> METHODOLOGY

The cost analysis assumes that provisions in the National Plan will follow closely or expand upon current demonstration projects conducted by the Centers for Medicare and Medicaid Services (CMS). The assumption is that the proposals will direct CMS to expand current study design to include people with Alzheimer's disease or replicate a previous demonstration with a study design that specifically focuses on individuals with dementia.³ The goal is to minimize costs while maximizing the evidence-based outcomes.

The cost analysis adheres to budget-scoring conventions and relies on current population estimates of individuals with Alzheimer's disease that are then projected over the 10-year budget-scoring window.⁴ The scoring analysis considers only the costs and savings associated with the federal budget and does not examine the considerable benefits that may accrue outside of the payment system, such as the savings and benefits for family caregivers.

This report provides two perspectives of the budget analysis of these AFA-selected provisions. The first perspective is a **cost analysis** that considers AFA proposals as new or expanded demonstration projects or proposals that integrate into existing Medicare systems. The purpose of this analysis is to put forward proposals that recognize the limitation of the existing budgetary climate, yet offer the potential to demonstrate benefits and cost savings.⁵

The second perspective of the budget analysis is the potential for **cost savings**, assuming the demonstration results provide quantifiable and measurable changes in the delivery of care. This analysis extends beyond the traditional budget-scoring process and provides estimates of potential savings, based on the anticipated results of the proposed demonstration projects.

The analysis of each demonstration project represents an independent examination of only the benefits of that proposal and does not account for interactions between various proposals. These estimates focus exclusively on cost savings and are illustrative in nature. However, the potential benefits through a reduction in costly services and interventions are significant. Even small changes in the delivery of care to individuals with

³ Section 1115 of the Social Security Act authorizes the CMS demonstration program. The annual CMS budget authority funds the operational aspects of the CMS demonstration program. However, if the program provides incentive payments or incurs additional costs, Congress must appropriate special funding for such programs. Historically, demonstration projects could not exceed \$8 million. On average, the appropriations for targeted populations with modest additional costs (and incentive payments) require approximately \$5 million for the entire demonstration project.

⁴ Budget-scoring conventions are the Congressional rules that guide the methodology used to evaluate the potential cost of proposed legislative changes. The costs include only those costs that are direct costs to the federal government. They do not include costs or savings that might accrue to private individuals, but only the costs or savings realized in the budgeting process.

⁵ The phrase "current budgetary climate" refers to the difficulty of passing legislation that may increase deficit spending – despite the importance of the legislation from a policy perspective.

Alzheimer's disease can result in large cost savings to the Medicare system, and these savings would continue beyond the current budget-scoring window.⁶

To realize these benefits in a formal budget analysis would require consideration of changes in the payment system—a policy change that was beyond the scope of this project. However, as AFA proposals advance through the legislative and regulatory process, it is possible to implement each in a budget-neutral manner or with proper financial incentives without altering the payment system.⁷

> THE CURRENT AND FUTURE STATE OF ALZHEIMER'S DISEASE

Alzheimer's disease is an irreversible, progressive brain disease that represents the most common form of dementia. Dementia is an umbrella term that describes a group of symptoms, such as loss of memory, judgment, language, complex motor skills, and other intellectual function, and personality changes, caused by the permanent damage or death of the brain's nerve cells, or neurons.

As many as 5.1 million Americans may have Alzheimer's disease.⁸ A recent study estimates that as Baby Boomers age, the number of Americans with Alzheimer's disease will nearly triple to 13.8 million by 2050.⁹

As the brain disorder progresses, typically over two to 20 years, both cognitive and behavioral symptoms develop and become more pronounced over time. These changes affect a person's ability to perform activities of daily living, such as eating, bathing and dressing. In the later stages, the person becomes unable to care for him or herself and experiences a loss of independence.

Alzheimer's disease is the sixth leading cause of death in America, though a recent study indicates that the death rate is underreported and that as many as 500,000 Americans die of Alzheimer's disease a year, potentially ranking it as the third leading cause of death.¹⁰ It is also the only growth category in the top 10 causes of death in the U.S., as recorded by the Centers for Disease Control and Prevention, and the only condition with no cure or treatment to reverse or slow its progression.

Individuals with Alzheimer's disease use a disproportionate amount of health care resources compared to people with other diseases. One factor attributable to the high cost of services (for Medicare beneficiaries in general as well as those with Alzheimer's disease) is the comorbidities that many Medicare beneficiaries with Alzheimer's disease have. These conditions complicate the delivery of care and require the need for multiple providers. For instance, people with Alzheimer's disease are hospitalized two to three times as often as people the same age who do not have the disease.¹¹ Similarly, more than half of all nursing home residents have Alzheimer's disease.¹²

⁶ Formal budget analyses do not consider the costs or savings beyond the 10-year budget window. However, as with other health care provisions, the Congressional Budget Office often makes qualitative statements regarding the potential for savings over the second 10-year period. The AFA proposals offer such savings potential in both the first and second 10-year scoring periods.

⁷ AFA recognizes that policy changes to the payment system from a cost-scoring perspective are an important aspect of advancing these proposals and plans to address these issues as it advances its' priorities.

⁸ Alzheimer disease in the United States (2010–2050) is estimated using the 2010 census, *Neurology* (March, 2013).

⁹ Ibid.

¹⁰ James, Bryan Ph. D., et. al., Contribution of Alzheimer disease to mortality in the United States, *Neurology*, March 5, 2014 (www.neurology.org/content/early/2014/03/05/WNL.0000000000000240.short). (www.caregiving.org/pdf/research/Alzheimers_Caregiving_Costs_Study_FINAL.pdf).

¹¹ CAREGIVING COSTS: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient, National Alliance for Caregiving, Nov, 2011 (www.caregiving.org/pdf/research/Alzheimers_Caregiving_Costs_Study_FINAL.pdf).

¹² See, Comparison of Characteristics of Nursing Homes and Other Residential Long-Term Care Settings for People With Dementia, AHRQ Publication No. 12(13)-EHC127-EF (www.ncbi.nlm.nih.gov/pubmedhealth/PMH0050127/) (approximately 45-67% of all nursing home residents have dementia).

In addition, for each person with Alzheimer’s disease, there are multiple caregivers, who respond to 24/7 needs related to activities of daily living. Caregiving duties often fall on family members who are overwhelmed both emotionally and physically, and whose health and well-being often suffer as they fulfill this role.¹³ There is a higher incidence of sickness and mortality among Alzheimer’s disease caregivers compared to other caregivers.¹⁴

For 2013, estimates project direct spending for Alzheimer’s disease at approximately \$203 billion.¹⁵ Researchers estimate that by 2050 this level of direct spending will reach \$1 trillion, if we do not address the current system for delivery of care. In 2010 alone, the cost of Alzheimer’s disease was estimated at \$109 billion for care purchased, and \$159 billion to \$215 billion when the monetary value of informal care is included.¹⁶

> COST ANALYSIS

For purposes of this document, AFA identified certain action steps in the National Plan that could advance the delivery of care for people with Alzheimer’s disease and their family caregivers—and that are vital to advancing this strategic plan. Ultimately, the analysis suggests that implementation of these provisions will eliminate costly medical interventions and will work to make significant improvements in the quality of life for diagnosed individuals and their family caregivers.

AFA-Selected Provisions

The proposals in the National Plan selected by AFA include:¹⁷

1. Medical homes for people with Alzheimer’s disease (2.E.1);
2. Independence at Home Demonstration (2.E.2);
3. Models of hospital safety for people with Alzheimer’s disease (2.F.1);
4. Models for effective care transitions (2.F.2);
5. Medicare Coordinated Care Models for people with Alzheimer’s disease (2.G.1); and
6. Support caregivers through call centers (3.B.7).

Rather than simply expand the delivery of care for all Medicare beneficiaries with Alzheimer’s disease, these proposals offer an opportunity to implement several demonstration projects that will identify those procedures and policies that offer the greatest benefit to both individuals with Alzheimer’s disease and their family caregivers. This would provide a transition from the broad recommendations in the National Plan to a proposed limited demonstration that would illustrate the effectiveness for broader implementation.

Previously, these demonstration projects introduced to the general Medicare population had uneven success. However, the analysis anticipates that with careful application to the Alzheimer’s population and by providing comprehensive care, the selected proposals would extend the successes realized in the early demonstration projects.

In addition, the proposed demonstrations consider the cost of implementing these provisions and make an effort to expand, eliminate, coordinate or condense existing programs to achieve the stated goals. It is also

¹³ CAREGIVING COSTS: Declining Health in the Alzheimer’s Caregiver as Dementia Increases in the Care Recipient, National Alliance for Caregiving, Nov, 2011.

¹⁴ Ibid.

¹⁵ Michael D. Hurd, Ph. D., et al., *Monetary Costs of Dementia in the United States*, New England Journal of Medicine, April 4, 2013.

¹⁶ Ibid.

¹⁷ References to the National Alzheimer’s Plan Act follow in parentheses after each provision.

important to recognize that strict cost-scoring conventions may recognize cost savings, yet benefits of such changes extend beyond simple expenditures by improving the quality of care and quality of life for people with Alzheimer’s disease and their family caregivers.

These provisions are consistent with the CMS’ guidelines on improving quality of care.¹⁸ The guidelines indicate that the majority of new quality improvements should be condition-specific, focusing on how individuals receive care (particularly for people with high-impact conditions and comorbidities). Analysis of quality in the delivery of care would focus on outcomes, resource use, and transitions of care.

This is also consistent with findings from the Congressional Budget Office (CBO). In an analysis of 34 Medicare demonstration projects or pilot projects, CBO found that reduced hospitalizations and cost savings occurred when there was significant in-person interaction between care managers and patients.¹⁹ Each of the proposed changes would require this personalized delivery of care and could result in cost savings.

It is important to note that current scoring conventions assume the incentives in fee-for-service Medicare encourage the delivery of more services, rather than efficient services. Further, the current scoring approach assumes that the current decentralized delivery of care is the baseline system. However, the selected provisions in the National Plan do address the decentralized delivery of care by calling for a health care coordinator: a primary care provider, under the Medical Homes provisions; a physician or nurse practitioner, under the Independence at Home provisions; and a patient-case manager relationship, under the Coordinated Care Model.

Therefore, using these demonstration projects to specifically target individuals with Alzheimer’s disease will provide concrete examples of the benefits of centralized care.²⁰

> MEDICAL HOMES FOR PEOPLE WITH ALZHEIMER’S DISEASE

Proposal Description

“Medical home” refers to a method of delivering health care that is coordinated, comprehensive, efficient and personalized. Practitioners and professional caregivers manage all aspects of a person’s care, not just treatment. The main purpose of medical homes is to improve quality of care, especially for people with high medical needs, such as individuals with Alzheimer’s disease. The goal is to provide coordinated care that prevents unnecessary services and potentially reduces the overall health care costs by targeting the precise needs of the person.

The following description modifies (for individuals with Alzheimer’s disease) previous demonstration projects that created or proposed medical home services.²¹

¹⁸ In most cases, the CBO does not recognize the cost savings of proposals that offer new services to Medicare beneficiaries. However, in the context of Alzheimer’s disease, there may be situations where the provisions reduce the potential for more costly medical interventions or improve significantly the quality of care and the quality of life for the beneficiary. The analysis will identify these situations, despite their absence from the cost estimate.

¹⁹ United States Congressional Budget Office, *Lessons from Medicare’s Demonstration Projects on Disease Management, Care Coordination, and Value-Based Payment*, Issue Brief, January 2012.

²⁰ It is important to note that in addition to coordinated care or centralized care, the programs would need to provide a bundled or capitated payment system to eliminate effectively the fee-for-service bias of the current Medicare payment system.

²¹ These sources include the current efforts by the Patient-Centered Medical Home (within AHRQ), private medical home associations, H.R. 6111, and the 1999 Medicare Demonstration for people with Alzheimer’s disease. One option to limit the overall outlay of this project is to establish a demonstration project tied to a fixed appropriation.

- Coordinate stakeholders (including professional societies, payers, local large employers/purchasers, healthcare-oriented community groups, patient advocacy groups, and representatives from local/regional quality improvement programs)
- Identify responsibilities of all participating parties (including providers, payers, diagnosed individuals/families and other relevant stakeholders), using a consensus-based process for quality control
- Provide participating practices with sufficient financial and non-financial support to at least cover the costs of the process; additional physician, clinical staff, and administrative staff work associated with the project; and implementation of the practice infrastructure required to provide services
- Maximize the number of individuals with Alzheimer's disease in each participating practice covered by the demonstration project, and by using targeted criteria for participation (by specifying the characteristics of those admitted to each practice, e.g., Medicare-eligible participants with Alzheimer's disease with specific chronic or non-chronic conditions)
- Develop a reimbursement model, including: (1) a prospective, bundled component that covers physician and administrative staff work and practice expenses linked to the delivery of services, (2) a performance-based component based on the achievement of defined quality and efficiency, and (3) an adjustment for the level of care provided considering the patient case mix/complexity)
- Provide an assessment of the results (over the duration of the project the participants will maintain a commitment to transparency of process, including the selection, use and reporting of results from clinical metrics, financial measures and the application of proprietary measures of performance)

CMS plans to test the patient-centered medical home model under the Innovation Center created by Section 3021 of the Patient Protection and Affordable Care Act (ACA). This provision allows CMS to test a variety of models and expand their implementation nationwide. The provision will proceed if the demonstration cuts spending without reducing quality or improves quality without increasing spending, and if CMS' chief actuary finds that expansion would not result in deficit spending. The demonstration will proceed if the Secretary of HHS determines that such an expansion would not result in denying or limiting coverage or the provision of benefits.

Cost Analysis

In 2011, CMS tested the patient-centered medical home model in the Multi-Payer Advanced Primary Care Practice Demonstration and the Federally Qualified Health Centers Advanced Primary Care Practice Demonstration. The results are not yet available. However, we assume the medical homes for people with Alzheimer's disease would (1) follow this original design; and (2) implement any results from the 2011 testing that may improve outcomes.

For budget-scoring purposes, the analysis assumes that this proposed demonstration would expand to include at least eight states with 15 additional sites.²² However, the provisions requiring budget neutrality (contained in the ACA) would apply to this demonstration as well.

The premise of the medical home model is that by providing coordinated, comprehensive and personalized care, medical homes will:

- reduce the need for emergency room visits;
- decrease hospital admissions (and readmissions);

²² This coverage is consistent with the provisions in the 2006 Medicare Act.

- shorten the average length of a hospital stay; and
- eliminate unnecessary tests and procedures.

All of these elements would contribute to overall cost savings. Moreover, this model is likely to improve the person's health, quality of care, and satisfaction, as well as provide multiple benefits to family caregivers.

The results of the medical home demonstration may be able to compare resource use among various providers or compare the resource use by specific episodes, and determine a clearer understanding of the highest quality of care for the most cost-effective delivery. Examining resource use along with other quality measures (e.g., such measures as outcomes), the demonstration can assess the efficiency of the services rendered and move toward achieving greater value in health care services.

Anticipated Benefits

If the Medical Home demonstration delivers coordinated, comprehensive care, it is likely that they could reduce hospitalizations for people with Alzheimer's disease. Consistent with other programs that relied on centralized care for patients, the medical home proposal could reduce hospitalizations for beneficiaries with Alzheimer's disease by seven percent.²³ By comparing the standard use for an episode of care to the overall resources used for a person with Alzheimer's disease, the medical homes can evaluate and identify use or overuse of a particular test or intervention. Currently, Medicare spends on average \$20,638 per beneficiary with Alzheimer's disease compared to only \$7,832 per beneficiary without Alzheimer's disease.²⁴ This represents a 164 percent increased level of spending for beneficiaries with Alzheimer's disease. Given that people with Alzheimer's disease have 780 hospitalizations per 1,000 Medicare beneficiaries with Alzheimer's disease, comprehensive, centralized care could address this use of in-patient hospitalizations.

In a fully phased-in model of medical homes, reducing the need for intensive medical services could reduce in-patient hospitalization spending by approximately \$2.5 billion in a given year. ***With the anticipated growth in the Medicare population of beneficiaries with Alzheimer's disease, reducing the need for hospitalization through medical homes could reduce costs by \$39 billion over 10 years if fully implemented.***

> INDEPENDENCE AT HOME (IAH) FOR PEOPLE WITH ALZHEIMER'S DISEASE

Proposal Description

The Independence at Home (IAH) Demonstration, currently being conducted by the Center for Medicare and Medicaid Innovation (CMMI), an arm of CMS, is testing a payment incentive and service delivery model that uses primary care teams led by physicians or nurse practitioners to deliver timely, in-home primary care to Medicare beneficiaries with multiple chronic illnesses and functional impairments.²⁵

One of the issues with relying on evidence from the current demonstration is that it does not focus specifically on individuals with Alzheimer's disease. However, people with Alzheimer's disease typically receive a higher level of services and experience higher rates of hospitalizations and emergency department visits

²³ This analysis is consistent with the CBO's evaluation of 34 Medicare demonstration projects.

²⁴ The Scan Foundation Data Brief: Medicare Spending on Beneficiaries With Dementia (http://thescanfoundation.org/sites/thescanfoundation.org/files/1pg_databrief_no30_medicare_spending_on_beneficiaries_with_dementia.pdf).

²⁵ For the purpose of this demonstration, "home" is simply where the beneficiary resides. A home may be a house, apartment, assisted living facility, or any other non-institutional location. Long-term residence in a nursing facility does not qualify as living at home for the purpose of this demonstration.

compared to the general Medicare population.

Under the requirements of the IAH Demonstration, participating practices must assess the effects of timely, in-home primary care on health care costs, quality of care, and rates of preventable hospitalizations, hospital readmissions, and emergency department visits over a three-year period.

In December 2011, CMMI released a call for applications for the IAH Demonstration. The center selected a total of 18 individual practices and consortia to participate in the IAH Demonstration. The eligible beneficiaries must meet certain criteria to participate, including:

- two or more chronic conditions;
- coverage from original, fee-for-service Medicare;
- require assistance with two or more functional dependencies (e.g., walking or feeding);
- had a non-elective hospital admission within the last 12 months; and
- received acute or sub-acute rehabilitation services in the last 12 months.

These eligibility requirements are typically consistent with the Alzheimer's disease population.

The participating practices are eligible for financial incentives if they are able to offer high-quality care that ultimately reduces the costs for Medicare beneficiaries with Alzheimer's disease. To qualify for an incentive payment, the practice's expenditures for participating beneficiaries must be lower than the calculated target expenditure, which represents the expected Medicare fee-for-service expenditures of participating beneficiaries in the absence of the IAH Demonstration. In order to minimize the outlays, the selected practices could expand their demonstration to include individuals with Alzheimer's disease.²⁶ Expanding this program would require an appropriation to cover such costs. The estimate of this additional cost is approximately \$5 million over the 10-year budget period.

Cost Analysis

Currently, an estimated 300,000 nursing home residents have a diagnosis of Alzheimer's disease.²⁷ This represents approximately 6.7 percent of all Medicare beneficiaries with Alzheimer's disease, but 15.5 percent of all nursing home residents. Medicare spends an average of \$18,353 annually on medical services per nursing home resident with Alzheimer's disease. In contrast, Medicare spends an average of \$1,401 annually on medical services per home health beneficiary with Alzheimer's disease.

The IAH Demonstration could offer savings through two different levels. First, by allowing people with Alzheimer's disease to receive quality care at home, the number and percent of the nursing home population with Alzheimer's disease could be reduced. Second, the coordinated in-home care could provide efficiencies in care delivery (as in the medical home provisions) through a centralized medical provider.

Anticipated Benefits

Reducing the number of nursing home residents with Alzheimer's disease by 10 percent would reduce Medicare spending by approximately \$800 million in a given year. Over 10 years, this cost saving increases to approximately \$11.4 billion. In addition, efficient in-home care could reduce unnecessary spending on medical services rendered when the beneficiary receives care in a medical facility. Reducing office visits and

²⁶ A detailed discussion is available at http://www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts/Downloads/IAH_FactSheet.pdf.

²⁷ This figure represents an estimate for 2013, based on data from the Centers for Disease Control and Prevention and the National Nursing Home Survey, available at: <http://www.cdc.gov/nchs/fastats/alzheimer.htm>.

hospitalizations could reduce the need for unnecessary tests and services. Since the vast majority of people with Alzheimer's disease are in non-nursing home settings, estimates indicate that Medicare spending could decrease by approximately \$1.5 billion in a given year. This translates to \$18.4 billion in cost savings over 10 years, given the current growth rate in services and in the number of people diagnosed with Alzheimer's disease. ***In total, the fully-implemented IAH program could reduce Medicare spending by approximately \$30 billion over 10 years.***

> MODELS OF HOSPITAL SAFETY FOR PEOPLE WITH ALZHEIMER'S DISEASE

Proposal Description

The following recommendations for protocols for emergency care departments and acute hospital settings treating people with Alzheimer's disease rely on many of the principles contained in a white paper, *Improving British Columbia's Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals*.²⁸ The recommended protocol design intends to help prevent unnecessary admissions for persons with Alzheimer's disease to emergency departments or acute care hospitals. It also contains recommendations and strategies for improving care for individuals with Alzheimer's disease in emergency departments and acute care hospitals.

Alzheimer's Disease Protocol for Emergency Departments

- Screen for delirium all patients who show indications of cognitive impairment.
- Provide appropriate triage for all patients with Alzheimer's disease and involve practitioners specifically trained in Alzheimer's disease.
- Improve interactions with caregivers as partners in care.
- Follow appropriate guidelines for managing behavior problems associated with Alzheimer's disease.
- Improve training of all personnel in the emergency department regarding appropriate care for persons with Alzheimer's disease.

Alzheimer's Disease Protocol for Acute Care Hospitals

- Focus on who the person is by following a person-centered care approach.
- Improve training of all hospital staff regarding appropriate care for persons with Alzheimer's disease.
- Follow appropriate behavioral protocols for patients demonstrating behavioral or psychological symptoms of Alzheimer's disease.
- Have a policy of minimal restraints (through staff education in "least restraints" policy and the rationale for it).
- Get consumer feedback and consumer involvement in care on the acute care units.

Approximately 31 percent of hospital admissions for individuals with Alzheimer's disease result from loss of consciousness (with interruption of awareness), trauma, delirium, and a change in mental status.²⁹

This indicates that patients with Alzheimer's disease may require specialized care to address these conditions as well as other underlying medical conditions.

²⁸ Donnelly, M., et al., *Improving British Columbia's Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals*, November 2011.

²⁹ Rudolph, J.L., N.M. Zanin, R.N. Jones, E.R. Marcantonio, T.G. Fong, F.M. Yang, S.K. Inouye, *Hospitalization in Community-dwelling Persons with Alzheimer's Disease: Frequency and Causes*, *Journal of American Gerontology Society*, 58(8), 2010.

Cost Analysis

In order to provide such specialized care without developing a separate (and potentially costly) program, we assume that CMS could modify certain provisions in the Hospital Inpatient Quality Reporting (Hospital IQR).³⁰ CMS has the authorization to pay hospitals that successfully report designated quality measures a higher annual update to their payment rates. This provision assumes that the Hospital IQR would expand to include the quality measures specified above.

Anticipated Benefits

The hospitals would have a financial incentive to improve and report the quality of their services provided to patients with Alzheimer's disease. In addition, the hospital reporting program will provide additional data to help policymakers make informed decisions about the services provided to patients with Alzheimer's disease. In addition, instituting dementia training and standards will help avoid complications, such as delirium, and lower rates of avoidable hospitalizations with accompanying cost savings.³¹

> MODELS FOR EFFECTIVE CARE TRANSITIONS FOR PEOPLE WITH ALZHEIMER'S DISEASE

Proposal Description

The current Community-based Care Transitions Program (CCTP) seeks to improve care transitions from the hospital to other settings, reduce readmissions for high-risk Medicare beneficiaries, enhance quality of care, and document measurable savings to the Medicare program through a community involvement approach. The proposal would expand the current CCTP to address the specific needs of people with Alzheimer's disease.

The CCTP provides funding to hospitals and community-based entities that furnish evidence-based care transition interventions to Medicare beneficiaries at high risk for readmission. Care transitions occur when a beneficiary moves from one health care provider or setting to another.

Traditionally, hospitals have served as the focal point to reduce readmissions, by examining the quality of care during the hospitalization and the discharge planning process. However, a number of factors along the care continuum influence readmissions. Identifying the key drivers of readmissions for a hospital is the first step towards creating necessary steps to reduce readmissions, particularly for individuals with Alzheimer's disease.³²

CCTP goals are to:

- reduce hospital readmissions;
- test sustainable funding streams for care transition services;
- maintain or improve quality of care; and
- document measureable savings to the Medicare program.

Cost Analysis

Community-based organizations (CBOs) will use care transition services to effectively manage the tran-

³⁰ Section 501(b) of the Medicare Prescription Drug, Improvement, and Modernization Act (MMA) of 2003 originally mandated this program. A description is available at <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/index.html>.

³¹ An analysis of 2005 Medicare claims data by the Medicare Payment Advisory Commission (MedPAC) concluded that about three-quarters of readmissions within 30 days were potentially preventable, representing an estimated \$12 billion in Medicare spending. See, Health Affairs, Health Policy Brief, Nov. 12, 2013 (http://healthaffairs.org/healthpolicy-briefs/brief_pdfs/healthpolicybrief_102.pdf).

³² Nearly one in five Medicare beneficiaries discharged from a hospital—approximately 2.6 million people—is readmitted within 30 days, at a cost exceeding \$26 billion every year.

sitions of Medicare beneficiaries and improve their quality of care.³³ Up to \$500 million in total funding is available for 2011 through 2015. The CBOs receive an all-inclusive rate per eligible discharge. The cost of transition services provided at the patient level and the cost of implementing systemic changes at the hospital level will influence the payment rate. CBOs receive one payment per eligible beneficiary discharge in a 180-day period. CBOs must provide care transition services across the continuum of care and have formal relationships with acute care hospitals and other providers along the continuum of care. For purposes of this analysis, we assume that CMS would use a portion of the existing appropriations to develop a model for effective care transitions for individuals with Alzheimer's disease.

Anticipated Benefits

When combined with the proper incentives (financial and non-financial), the use of care coordination measures could create cost savings in two ways. First, by coordinating care for people with Alzheimer's disease, the program could reduce the number and percent of the hospitalizations through preventive care. Second, the care coordination program could provide efficiencies in care delivery by reducing the level of services provided.

> MEDICARE COORDINATED CARE MODELS FOR PEOPLE WITH ALZHEIMER'S DISEASE

Proposal Description

The Medicare Coordinated Care Demonstration (MCCD) tested whether case management and disease management programs can lower costs and improve patient outcomes in the Medicare fee-for-service population.

In 2002, this MCCD selected 15 demonstration programs in a competitive awards process; each defined its own intervention and target population within broad parameters. Each program enrolled participants (between April and September of that year) and received authorization to operate for four years.³⁴

The successful programs shared several features, namely:

- careful planning of patient care and patient education;
- strong patient-case manager relationships;
- early detection of health problems to limit or prevent future problems;
- use of evidence-based intervention guidelines; and
- experienced nurses serving as care coordinators.

The proposed provision would build upon this demonstration project and follow a similar protocol, but it would only serve people with Alzheimer's disease and specifically address the need for coordinated care for this population. The design for the MCCD for Alzheimer's disease will rely on CMS' assessment of best practices in coordinated care.

³³ A detailed discussion is available at <http://www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts/Medicare-Demonstrations-Items/CMS1198864.html?DLPage=1&DLFilter=care%20coord&DL-Sort=2&DLSortDir=descending>

³⁴ The evaluator, Mathematica Policy Research, Inc., randomly assigned beneficiaries to either the treatment group, which received the intervention, or the control group, which did not. Both groups continued to obtain their traditional Medicare-covered services from fee-for-service providers in the usual manner.

The MCCD for individuals with Alzheimer’s disease has three goals:

1. Provide CMS with unbiased estimates of the demonstration programs to provide better and more cost-effective care for Medicare beneficiaries with Alzheimer’s disease
2. Assess the extent to which the care coordination benefits depend on participant and program characteristics
3. Provide guidance on the possible structure of a Medicare coordinated care benefit

Cost Analysis

When combined with the proper incentives (financial and non-financial), the use of care coordination measures could create cost savings in two ways. First, by coordinating care for people with Alzheimer’s disease, the program could reduce the number and percent of hospitalizations through preventive care. Second, the care coordination program could provide efficiencies in care delivery by reducing the level of services provided.

Anticipated Benefits

In a fully phased-in model of care coordination, this could reduce in-patient hospitalization spending by approximately \$1.6 billion in a given year. With the anticipated growth in the population of Medicare beneficiaries with Alzheimer’s disease, reducing the need for hospitalization through care coordination models could cut costs by \$24.4 billion over 10 years. In addition, care coordination models could decrease Medicare spending by approximately \$1.3 billion in a given year. This translates to \$16.4 billion in cost savings over 10 years, given the current growth rate in services and increased number of people with Alzheimer’s disease. ***In total, the fully-implemented care coordination program could reduce Medicare spending by approximately \$41 billion over 10 years.***

> SUPPORT CAREGIVERS OF PEOPLE WITH ALZHEIMER’S DISEASE THROUGH CALL CENTERS

Proposal Description

Currently, a national call center is operating, with funding from the Administration for Community Living (ACL). In 2010, ACL solicited applicants for grants to create a National Alzheimer’s Call Center to provide personalized, professional *Information Service and Care Consultation Service*.³⁵ The plan calls for making the services available 24 hours a day, each day at the national and local levels.³⁶

The intent of this proposal is not to establish a separate national call center, but rather enhance existing services. The expanded and enhanced National Alzheimer’s Call Center would provide free of charge timely, accurate, personalized and comprehensive expert advice by licensed social workers; consultations on care, services and crisis response; and information and referrals (non-exclusive) at national and local levels in all 50 states and territories—features that go beyond what is currently available at the federally-funded National Alzheimer’s Call Center. The center would serve individuals with Alzheimer’s disease and their families and informal caregivers in order to educate them about the disease and support services, and ultimately improve their quality of life. It includes characteristics of AFA’s current helpline, such as staffing by licensed

³⁵ In September, 2013 the Administration for Community Living granted the Alzheimer’s Association up to \$985,135 per year over five years to provide a 24-hour phone line for people with Alzheimer’s disease and those who care for them. The information line made possible by this grant provides expert advice, care consultation, counseling and referrals to services that maximize independence and well-being at the national and local levels to callers from 56 states and territories, 7 days a week, 365 days a year. See, www.aoa.gov/AoARoot/Resource_Centers/Consumers.aspx#consumer3.

³⁶ Ibid.

social workers; multiple methods of communication (i.e., phone, e-mail, Skype, live chat); and non-exclusive referrals to resources.

The call center objectives are to:

- provide callers with professional personalized counseling and crisis response from licensed masters' level social workers;
- offer various communication methods, including phone, e-mail, Skype and live chat;
- provide education about Alzheimer's disease and related issues, such as caregiving and current research related to the brain disorder;
- connect callers through a seamless nationwide referral network (non-exclusive) to national, state and local agencies and community organizations, both governmental and non-governmental, which offer hands-on services;
- encourage early intervention, proper diagnosis, medical treatment, and care options through the utilization of community-based educational and social services;
- target under-served minority populations with appropriate and culturally-sensitive information on Alzheimer's disease and services available (in English, Spanish and other languages, as needed); and
- raise awareness of the disease and its economic and social impact on families and communities through a national marketing strategy and collaboration with appropriate organizations that would highlight the services provided by the call center.

Customers will include consumers, including people with Alzheimer's disease, caregivers, family members, and the public.³⁷ The program will integrate with the work of local agencies and organizations involved in providing services and support to people affected by Alzheimer's disease, without duplicating such services.

Staffing requires professional customer service staff and master's degree or equivalent social workers/counselors. The call centers will have the capacity to respond to many languages through translation services.³⁸

During regular business hours, calls to the toll-free number would go to local service agencies that offer detailed information and immediate counseling services (including crisis counseling). These local agencies will provide services to ensure that consumers receive appropriate and high-quality responses to their concerns. After regular business hours and on weekends and holidays, the program will maintain constant staffing to ensure continuous access. The center will have the capability of serving long-distance caregivers through telephone conferencing and transfer capabilities between caregivers' and the family members' communities.

Cost Analysis

The current funding level for the grants is \$985,135 (for a single five-year award). To expand such services, it would be necessary to appropriate additional resources. The analysis assumes that in addition to the base grant, an additional \$500,000 five-year grant would be necessary to ensure adequate provision of the expanded services.

³⁷ The National Alzheimer's Call Center will not serve health care providers or other professionals, as other existing resources are available for assisting health care providers and other professionals to learn about and respond to issues facing people affected by Alzheimer's disease.

³⁸ The National Alzheimer's Call Center will have multilingual capacity and will respond to inquiries in at least 140 languages through its own bilingual staff and with the use of language translation/interpretation services.

Anticipated Benefits

When an individual is diagnosed with Alzheimer's disease, a family member (i.e., spouse, adult child, grandchild) is often left alone to meet the challenges of caregiving with little or no education or training about the disorder or caregiving. Yet, studies have shown the effectiveness of a counseling and support intervention for spousal caregivers in delaying nursing home placement of loved ones with Alzheimer's disease.³⁹ Even a small delay in nursing home placement will save millions of dollars in costs and allow for more positive health outcomes for both the individual with Alzheimer's disease and the family caregiver.

One such study looked at a spousal intervention program that consisted of six sessions of individual and family counseling, support group participation, and continuous availability of ad-hoc telephone counseling.⁴⁰ Individuals with Alzheimer's disease whose spouse received the intervention experienced a 28.3 percent reduction in the rate of nursing home placement compared with usual care controls.⁴¹ The difference in model-predicted median time to placement was 557 days.⁴² In addition, there were significant improvements in caregivers' satisfaction with social support, response to behavior problems and symptoms of depression.

Greater access to effective education, counseling and support could yield considerable benefits for caregivers and cost savings to federal health programs through deferred nursing home placements of individuals with Alzheimer's disease and improved caregiver health.

> CONCLUSION

Patient-centered, coordinated care delivery models and expansion of caregiver training and supports will help bend the astronomic cost curve necessary to care for a person with Alzheimer's disease, while increasing healthier outcomes for diagnosed individuals and family caregivers. The National Plan provides policy-makers with the strategies and goals related to these action steps, adopting delivery reforms, and expanding services and supports for individuals with Alzheimer's disease and their caregivers. It's time now for policy-makers to deliver.

In this era of fiscal restraint, innovative delivery reforms and smart investments in caregiver supports and training will extend limited resources by lowering overall costs of care for a person with Alzheimer's disease. Coordinated care delivery that avoids unnecessary hospitalizations and provides tools to caregivers that delay nursing home placement are necessary policy changes that will allow Americans to provide quality care until such time as clinical research provides a cure or effective treatment for this fatal brain disorder.

Utilizing this cost analysis, AFA will continue working with Congress, the Administration and other advocates to advance these cost-effective approaches as our nation searches for solutions to ensure that the growing number of individuals with Alzheimer's disease and their families have access to critical care services and family supports that are effective from both cost and quality standpoints.

³⁹ Mary S. Mittelman, DrPH et. al., Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease (www.neurology.org/content/67/9/1592.abstract).

⁴⁰ Ibid.

⁴¹ Ibid.

⁴² Ibid.

> APPENDIX

TABLE 1 – Estimated Cost of Certain Proposals to Improve the Delivery and Quality of Care for Beneficiaries With Alzheimer’s Disease and Their Caregivers

Proposal	10-Year Budget Period
Medical homes for AD demonstration	Budget neutral
Independence at Home demonstration	\$5 million
Models of hospital safety for people with AD	Integrate into existing hospital IQR program
Models for effective care transitions	No cost
Care coordination models demonstration for people with AD	\$4 million
Support caregivers through call centers	\$500,000
Total Outlays	\$10 million

TABLE 2 – Estimated Cost Savings of Certain Proposals to Improve the Delivery and Quality of Care for Beneficiaries With Alzheimer’s Disease and Their Caregivers

Proposal	10-Year Budget Period
Medical homes for AD demonstration	\$39 billion
Independence at Home demonstration	\$30 billion
Models of hospital safety for people with AD	<i>No quantifiable estimate</i>
Models for effective care transitions	<i>No quantifiable estimate</i>
Care coordination models demonstration for people with AD	\$41 billion
Support caregivers through call centers	<i>No quantifiable estimate</i>
Total Savings	\$110 billion

> CONTRIBUTORS

This report, “Cost of Care: Quantifying Care-Centered Provisions of the ‘National Plan to Address Alzheimer’s Disease,’” is a project of the Alzheimer’s Foundation of America (AFA). AFA is a leading national nonprofit organization dedicated to providing optimal care and services to individuals with Alzheimer’s disease and their families. Uniting 1,600 member organizations nationwide, it provides services and initiatives aimed at reducing the practical, emotional and financial toll of Alzheimer’s disease, and advocates for increased funding for research toward a cure and expanded supportive services for people with the disease and their caregivers.

AFA contracted with Quantria, LLC, a Virginia-based company with more than 40 years’ experience in analysis and design for legislative and policy initiatives, to prepare this analysis. Judy Xanthopoulos, Ph.D., principal and co-founder of Quantria, LLC, performed the cost analysis.

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