

**Statement of  
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**Before the  
Special Committee on Aging  
United States Senate**

**March 25, 2009**

Chairman Kohl and Members of the Committee, who among us does not know someone who has been diagnosed with Alzheimer's Disease? And who among us does not know someone who has provided care for a loved one with the disease?

Alzheimer's disease turns out the light of memory. For good and bad the victim becomes someone else. But the disease does more than destroy memory. It destroys the capacity for daily functioning. Dependency is a universal condition for those who suffer the disease's destruction of healthy brain tissue. Independent living is not possible following a steady decline in memory and mental abilities.

Alzheimer's disease is not a part of normal aging. It is a disease. Still, the risk of the disorder increases with age. About 5 percent of people between the ages of 65 and 74 have Alzheimer's disease, while nearly half the people over the age of 85 have Alzheimer's.

These two simple facts – universal dependency and high probability of acquisition beyond the age of 80 – combined with a growing number of Americans who will live that long or longer have profound significance for every member of Congress. For you have the responsibility every year of authorizing two programs – Medicare and Medicaid – which will be severely stressed by the mounting cost of this disease.

Alzheimer's is not just another disease that produces suffering. Victims of other well known and researched diseases very often function normally in all other respects other than their treatment and do not require the kind of intense and expensive dependent care that always accompanies Alzheimer's. Curing Alzheimer's will do more than save lives; it could save our health care system from financial collapse.

The sobering implications of this mounting Alzheimer's crisis led the Alzheimer's Study Group to this principal recommendation:<sup>1</sup>

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<sup>1</sup> This recommendation is from the Alzheimer's Study Group's report, *A National Alzheimer's Strategic Plan*, which can be accessed at [www.alzstudygroup.org](http://www.alzstudygroup.org).

***Establish the Alzheimer's Solutions Project to accelerate and focus national efforts, reengineer dementia care delivery, and, ultimately, prevent Alzheimer's disease.***

The Alzheimer's Study Group urges America to embark on this bold project to contain the staggering impact of Alzheimer's disease. The project is composed of three initiatives:

1. ***The Alzheimer's Prevention Initiative:*** As a national priority, urgently focus on developing the capability to delay and, ultimately, prevent Alzheimer's disease. This capability will depend on the advancement of development science as well as basic research.
2. ***The Alzheimer's Care Improvement Initiative:*** By 2012, use value-based payments to reimburse providers for at least 20 percent of health and social services for people with dementia, and for half of these services by 2016. Value-based payments will reward health care and social services professionals for providing the coordinated care dementia patients most need for better health and a higher quality of life.
3. ***The Alzheimer's Public-Private Partnership:*** By 2010, establish an outcomes-oriented, project-focused Alzheimer's Solutions Project Office within the Federal Government. Backed by an appropriate scale of funding and through active collaboration with other stakeholders outside the Federal Government, this office will lead the successful implementation of the Alzheimer's Prevention and the Alzheimer's Care Improvement Initiatives, together with supporting efforts.

***The Alzheimer's Prevention Initiative***

Our consultations with the Alzheimer's research community have made two points clear to us:

- Many leading Alzheimer's researchers believe that we may be closing in on developing the capability to delay, and even prevent, Alzheimer's.
- However, developing this capability as quickly as possible will require us to abandon a "business as usual" approach to overcoming these challenges.

And this analysis led us to propose the Alzheimer's Prevention Initiative, the objective of which is developing the capability to delay and, ultimately, prevent Alzheimer's disease. This capability will depend on the advancement of development science as well as basic research.

The most important recommendations to advance in pursuit of this initiative can be summarized as follows:

1. ***Clarify and accelerate the development pathway for preventive and risk-reducing therapies.*** The Alzheimer's Solutions Project must work with a range of stakeholders to clarify and streamline the development pathway for preventive and risk-reducing therapies. This effort should aim to advance development science, including the improvement of disease models and qualification of biomarkers for clinical research. Additionally, incentives for exploring potentially significant lifestyle interventions, such as diet and exercise, are insufficient. Both pharmacological and behavioral interventions must be accelerated if we are to develop the capability to prevent Alzheimer's as quickly as possible.
2. ***Expand the volunteer research pool.*** Much larger numbers of volunteers—including study participants who have Alzheimer's and control group participants who do not—should be recruited for clinical trials and population-based longitudinal studies to build our understanding of the disease and validate potential interventions. Recruitment of pre-symptomatic and early-stage patients is especially critical to the development of preventive treatments.
3. ***Encourage rapid learning by linking databases and researchers.*** Create an Alzheimer's disease rapid-learning network that links all major research databases and researchers. Implement advanced analytical tools to support research and data mining using this new data-sharing infrastructure.

Many experts believe we may be on the cusp of developing the capability to prevent Alzheimer's disease. However, this goal will only be reached if we pursue it with discipline regarding the ends and innovation regarding the means.

### ***The Alzheimer's Care Improvement Initiative***

While we focus on the search for a cure, we must also vastly improve how we deliver Alzheimer's care. The most important lever for doing so, we have concluded, is payment reform.

Nothing shapes practice as profoundly as payments. From workforce recruitment and retention, to procedures and practice patterns, Medicare and Medicaid reimbursement schedules and methods have a significant effect on the care that patients do—or do not—receive.

This fact is at the root of a fundamental problem facing people with Alzheimer's disease or other dementias and their caregivers. Many of these families depend on Medicare Fee-for-Service to cover the costs of care. Unfortunately, Medicare Fee-for-Service leads to very poor care for people with Alzheimer's disease and other dementias.

Medicare Fee-for-Service rewards volume. The more patients a health professional can serve and the more services that professional can offer in a fixed amount of time, the higher his or her income will be. Yet, the best dementia care—and very likely the cheapest dementia overall as well—is low volume. The more time a health professional spends with patients and their caregivers, the better the care will be.

Medicare Fee-for-Service discourages coordinated care. Yet, people with Alzheimer's or other dementias require care coordination given the prevalence of co-morbidities and their diminished capacity to manage their own health.

Medicare Fee-for-Service currently provides low reimbursement—or no reimbursement at all—for services like counseling and medication management. Yet services like these best suit the needs of dementia patients.

Medicare Fee-for-Service discourages the use of community services and psychosocial interventions. Yet these services often provide the greatest value to dementia patients.

Perhaps the failure of the current system is best illustrated by the fact that fewer than half of those with dementia even have their condition noted on their medical records, despite the sweeping implications such a diagnosis should have on care plans, medications, referrals, and other issues. Health care providers fail to diagnose many cases of dementia for several reasons, but perhaps the most important is that they lack the financial incentive to do so. Not only is a diagnostic workup itself reimbursed poorly compared to many other Medicare services, but a diagnosis sets in motion a chain of other responsibilities that are also poorly reimbursed under Fee-For-Service.

Individuals with Alzheimer's disease or other dementias need a Medicare reimbursement system that rewards value, not volume. This new system should be based on a simple economic principle. Care providers—much like all providers of goods and services in the marketplace—should be rewarded for providing what is most valuable to dementia patients for better health and a higher quality of life.

Our challenge is to determine what dementia patients and their families value most, to develop systems to measure appropriate care delivery, and to reward providers for delivering such care.

In our report, the Alzheimer's Study Group has developed a range of recommendations aimed at reforming health and community care systems so they were more responsive to the needs of people with Alzheimer's and other dementias. The following points summarize the recommendations that should receive the highest priority as we work to fundamentally reform the payment system as a way to improve outcomes across health systems and communities:

1. ***Implement an electronic health records system.*** Such a system can be used to track the delivery of valued care and lower the cost of care coordination.

2. ***Develop quality care measures.*** These measures should be based on what people with Alzheimer's disease and their caregivers value most. Building on this work, begin to test value-based payments for dementia care based on a small number of indicators in pilot programs, followed by aggressive rollout as results warrant.
3. ***Encourage coordinated care.*** This care should include training and supporting family caregivers, who often bear the largest share of the caregiving burden today without compensation.

Our ultimate hope and ultimate goal is a world without Alzheimer's disease. While we work toward that goal, we also have a responsibility to create a system that delivers more valuable and efficient care for the 5.3 million Americans with Alzheimer's today, and the almost half a million additional Americans who develop Alzheimer's every year. In that effort, we must implement a value-based payment system that will drive change and spur care delivery innovation. Americans with Alzheimer's deserve much better care than they all too often receive today.

### ***The Alzheimer's Public-Private Partnership***

Despite the grave implications of the mounting Alzheimer's disease crisis for America's future, the Federal Government has no comprehensive strategy to guide its efforts against this disease. There is no integrated statement of the vision, assumptions, objectives, strategies, measures of success, assignment of responsibilities, timelines, and anticipated resource requirements to guide and explain the Federal Government's overarching efforts to address the Alzheimer's crisis. In fact, our review indicates that there exists nothing even close to the kind of planning document routinely employed to guide disciplined, comprehensive and sustained planning and implementation efforts.

The Alzheimer's Solutions Project will fill this void. Through the Public-Private Partnership, it will take a system-wide approach to planning and implementation that accounts not only for the various agencies and departments of the Federal Government, but will actively work to coordinate and align these efforts with those of other key stakeholders outside the Executive Branch.

In addition to an agile, project management approach, the Alzheimer's Solutions Project will require investment levels significantly above current levels. It should be noted, however, that these investment levels will almost certainly remain modest relative to the most appropriate financial reference points, such as the project's potential return on investment. That is, the appropriate comparison should be the potential of such an investment to offset the projected \$20 trillion Federal expenditure to pay for the care of people with Alzheimer's over the next generation.

This standard return on investment framework brings reasonable investment levels into clearer perspective. A total investment of \$50 billion over the course of the Alzheimer's

Solutions Project would pay for itself many times over even if it only managed to yield a 1 percent reduction in the projected \$20 trillion outlay. If it led to the capability to prevent Alzheimer's, it would prove to be one of the wisest and most profitable investments in the history of our Nation. And this is before even factoring in the improvements such an investment would bring to the quality of life of millions of Americans.

While the federal investment should be substantial enough to allow researchers to make significant progress toward Alzheimer's prevention and better care solutions, the Federal Government should not be the only contributor to this effort. Federal investment must be designed to attract, not crowd out, additional investments from other stakeholders. Just as they already do today, for- and non-profit sectors alike should be encouraged to continue to contribute to this effort, both in dollars and in expertise. Individuals employed within these sectors have already shown that they possess knowledge and experience that will be indispensable to the pursuit of solutions to important aspects of the Alzheimer's disease crisis.

The same is true of state and local governments. These governments are often ahead of the Federal Government in their efforts to address pressing issues such as the development of effective and sustainable community-based care models. In addition, states like Arizona, Florida, and Texas are spearheading the creation of innovative public-private research consortia that are already yielding impressive results.

Collaboration is also warranted on the international level. Global partners such as France, the United Kingdom, and Japan have engaged in national planning exercises that hold important lessons for U.S. efforts. The United States should actively engage with international partners through the G8, the World Health Organization, and other multilateral organizations.

The Alzheimer's Study Group believes that by 2010 Congress should establish an outcomes-oriented, project-focused Alzheimer's Solutions Project Office within the Federal Government. Backed by an appropriate scale of funding to finance projects and through active collaboration with other stakeholders outside the Federal Government, this office will lead the successful implementation of the Alzheimer's Prevention and the Alzheimer's Care Improvement Initiatives, together with supporting efforts.

The Alzheimer's Study Group has developed a range of recommendations regarding the appropriate governance structure for a sustained, appropriated funded effort to overcome the Alzheimer's crisis. In summary, the following recommendations are most important to successfully completing the Public-Private Partnership Initiative:

1. ***Create an Alzheimer's Solutions Project Office.*** This office should exist within the Executive Branch and should be led by a Chief Executive Officer. As its first order of business, the office should develop and publicly release a detailed Alzheimer's Solutions Project Implementation Plan. The plan should be publicly updated with accompanying progress reports no less than annually.

2. ***Put at the disposal of the office an Alzheimer's Solutions Project Investment Fund.*** Annual appropriations to the fund should be based on a multiyear investment budget that extends through at least a five year planning cycle. Appropriate funding levels should be revisited annually to address the rate of progress and changing conditions. The scale of Federal investment should be based on the savings that overcoming Alzheimer's would yield to the Federal government over the coming generation, implying a scale of annual investment many times greater than current levels.
3. ***Maximize public-private collaboration to speed progress.*** Building on current initiatives and existing efforts, maximize public-private collaboration wherever feasible. Quickly implement such initiatives while balancing the need for speed and innovation with the need for appropriate safeguards and controls.

The Alzheimer's Public-Private Partnership Initiative is a critical foundation for the successful execution of the other Alzheimer's Solutions Project initiatives. Implemented effectively, the project will allow the country to begin providing Alzheimer's and other dementia care much more effectively by 2012, and will provide the capability to prevent Alzheimer's as quickly as possible. Without this program infrastructure in place, however, these objectives will most likely remain out of reach.

Mr. Chairman and Members of this Committee, Alzheimer's disease has placed America's future at risk. Without substantial progress toward overcoming this disease, millions of Americans and their families will suffer the devastating, progressive loss that comes with Alzheimer's. In addition, all Americans will shoulder the fiscal burden of a costly disease that promises to substantially increase Medicare and Medicaid spending in the years ahead.

The Alzheimer's Study Group believes we can secure a much better future for our Nation. Through the implementation and successful execution of these initiatives, America will travel a path to a much better world—a world without Alzheimer's.

Allow me to close with a quote of Albert Einstein:

“A human being is part of a whole, called by us the Universe, a part limited in time and space. He experiences himself, his thoughts and feelings, as something separated from the rest a kind of optical delusion of his consciousness. This delusion is a kind of prison for us, restricting us to our personal desires and to affection for a few persons nearest us. Our task must be to free ourselves from this prison by widening our circles of compassion to embrace all living creatures and the whole of nature in its beauty.”

Much the same needs to be done with our collective effort to find a cure for Alzheimer's. We must free ourselves from the prison of the status quo in order to create the possibilities of a different way of growing old.

Thank you.