

Advisory Council on Alzheimer's Research, Care, and Services

April 17, 2012

Clinical Care Subcommittee Recommendations

Laurel Coleman, Chair
Eric Hall
Helen Matheny
Bruce Finke
Shari Ling
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Recommendation 1

- ▶ HHS should launch a nationwide public awareness campaign to increase awareness and to promote early detection of Alzheimer's disease.

Recommendation 2

- ▶ Redesign Medicare coverage and physician reimbursement to encourage diagnosis of Alzheimer's disease and to provide care planning to diagnosed individuals and their caregivers.

Recommendation 3

- ▶ HHS should develop quality indicators for the care and treatment of individuals with Alzheimer's.

Recommendation 4

- ▶ HHS should provide grants through the Center for Medicare and Medicaid Innovation (CMMI) for medical home pilot projects specifically targeted at improving medical management for individuals with Alzheimer's disease, including management of co-existing medical conditions and coordination with family and community care providers in all settings (in-home care, long-term care, and inpatient hospital care).

Recommendation 5

- ▶ HHS should form a blue ribbon panel of experts to recommend one or more models of palliative care for people with advanced dementia, including eligibility criteria and financing mechanisms, and provide grants through the Center for Medicare and Medicaid Innovation (CMMI) to implement and evaluate the models.

Recommendation 6

- ▶ HHS should create a specific grant round of pilot projects through the Center for Medicare and Medicaid Innovation (CMMI) to implement and evaluate ways to reduce potentially preventable emergency department visits and hospitalizations for individuals with Alzheimer's disease and other dementias, including emergency department visits and hospitalizations from home, assisted living facilities, and nursing homes.

Recommendation 7

- ▶ Develop a public-private partnership to develop and evaluate ways to improve hospital care and transitions of care for people with Alzheimer's and other dementias, including training approaches and proposed quality measures.

Recommendation 8

- ▶ Expand funding and incentives for health care providers to become more knowledgeable about dementia and to encourage individuals to pursue careers in geriatric specialties.

Discussion

Clinical Care Subcommittee
Recommendations

Long-Term Services & Supports Subcommittee Recommendations

David Hoffman, Chair
David Hyde Pierce
Laura Trejo
Geraldine Woolfolk
Jim Burris
Laura Lawrence
Bill Spector

Recommendation 1

- ▶ HHS should provide Federal Funds to support a state lead entity in every state and territory. This entity would coordinate available public and private LTSS, conduct service gap analysis, identify opportunities for efficiency, and enable ongoing stakeholder input to address needs across all sectors and systems.

Recommendation 2

- ▶ Recommended use of Federal Funds (\$10.5 million) currently allocated to AoA
 - HHS (AoA) should use the \$10.5 million for state grants to seed the development of state action plans that maximize use of public and private resources to support services.
 - Governor's should designate the "State Lead Entity" and commit to sharing a state plan with recommendations for action publically.
 - State agencies and relevant partners should be included.
 - Match should be required to expand impact.
 - This should be expanded in future years with additional resources.
 - Estimated funds necessary to fully fund all states = \$85 million.

Recommendation 3

- ▶ Funding for the Alzheimer's Disease Supportive Services Program (ADSSP) should be restored to the FFY 2003 level of \$13.4 million.

Recommendation 4

- ▶ Fully fund Caregiver Supports under AoA

Recommendation 5

- ▶ Assure a robust, dementia capable system of Long Term Services and Supports (LTSS) is available in every state.

Recommendation 6

- ▶ States should ensure that Paraprofessional Caregivers in every venue are adequately trained and compensated

Recommendation 7

- ▶ **LTSS systems should refer to a healthcare provider for diagnosis whenever someone is admitted to/assessed for eligibility for LTSS and exhibits signs of cognitive impairment. Providers engaged in diagnosis should consider the 2011 Guidelines for Diagnosis.**

Recommendation 8

- ▶ **The Process of diagnosis should include engaging individual and family in advance care planning (health, estate and financial).**

Recommendation 9

- ▶ Recommendations for end-of-life/ palliative care should be incorporated into all surveillance and QI systems (specific – CMS).

Recommendation 10

- ▶ Practice recommendations for care in every setting should be embedded in Federal and State surveillance and QI systems (specific – CMS).

Recommendation 1 1

- ▶ HHS should assure that health and related systems funded with Federal resources should improve chronic disease treatment and related services for people with Alzheimer's disease.

Recommendation 1 2

- ▶ HHS and State Lead Entities should assure that caregiver physical health/ behavioral health risk is assessed and addressed regularly. Caregiver illness and mortality contribute to the enormous personal and financial cost of Alzheimer's disease.

Recommendation 13

- ▶ In partnership, HHS and State Lead Entities should assure access to the full array of LTSS for special and emerging populations of people with Alzheimer's disease including younger people, people with developmental disabilities such as Downs Syndrome, and others.

Recommendation 14

- ▶ State Education and Health agencies and others should include key information about Alzheimer's disease in all curricula for any profession or career track effecting long term services and supports.

Recommendation 15

- ▶ The Office of the National Coordinator, in partnership with the private sector, should assure that development of health information technology should include tools for caregivers to assist in the care of the person with Alzheimer's disease to address dementia and multiple chronic conditions as well as maintain their own mental and physical health.

Discussion

Long-Term Services and Supports
Subcommittee Recommendations

Research Sub-Committee Recommendations

Harry Johns
Jennifer Manly
Ronald Petersen
George Vradenburg
Richard Hodes
Russell Katz
Donald Moulds

Introduction

- ▶ **Research recommendations were developed along four strategic themes:**
 - Commit resources with accountability
 - Accelerate basic and translational research toward development of effective treatments
 - Maximizing private investment to develop treatments and improve disease monitoring technology
 - Meaningfully coordinate with global partners

Recommendation 1

We support and applaud the goal of the National Plan -- to prevent and effectively treat Alzheimer's Disease by 2025.

- ▶ Development of interim milestones, such as a significant disease-modifying or substantially-enhanced symptom-mitigating behavioral or pharmacologic intervention by 2020.
- ▶ New investment in research must reflect a critical balance between basic research and the urgency treatment discovery.

Recommendation 2

- ▶ There is an urgent need for annual federal research funding to be increased to the level needed to fund a strategic research plan and to achieve the breakthroughs required to meet the 2025 goal. Initial estimates of that level are \$2 billion per year but may be more. That investment would be applied to Alzheimer's research initiatives spanning basic, translational and clinical research.

Recommendation 3

- ▶ We recommend that HHS develop, execute and regularly update a strategic research plan and priorities to accelerate breakthroughs in AD research.

Recommendation 4

- ▶ We recommend that the Administration designate specific Offices and officials within the White House and the Office of the Secretary of HHS with responsibility and accountability for effective implementation of, and timely, transparent reporting on, all aspects of the implementation of this National Alzheimer's Plan, including responsibility for issuing statutorily required reports to Congress on behalf of the Secretary, reports to the Advisory Council, and other reports as warranted.

Recommendation 5

- ▶ We recommend that HHS, in partnership with the research community and industry, take steps to accelerate public access to new therapeutic interventions by compressing the current average time in the process of identification of therapeutic targets, validation of those targets, development of behavioral and pharmacologic interventions, testing of efficacy and safety, and regulatory review.

Recommendation 6

- ▶ We recommend that the Secretary, in consultation with academic researchers, not-for-profit Alzheimer's organizations, and the private sector, including sponsors of investigational diagnostic and therapy trials, by year-end 2012 identify and prioritize the action steps needed to reduce the time for moving therapies from target identification and validation through clinical development, regulatory review, market approval, and reimbursement determinations.

Recommendation 7

We recommend that the Secretary examine and include as part of her annual report to Congress and the Advisory Council:

- ▶ How the HHS will reduce barriers and accelerate development of new therapies
- ▶ Immediate steps the HHS will take to address any identified drug development barriers,
- ▶ Additional authorities or other legislative action that may be needed to accelerate development of therapies and diagnostics
- ▶ Immediate steps to shorten time from market approval to coverage decision

Recommendation 8

- ▶ We recommend that the FDA review and periodically report to the Advisory Council recommendations to further accelerate FDA review processes without compromising current standards of safety and efficacy.

Recommendation 9

- ▶ We recommend that the HHS Secretary develop a continuing process by which research priorities aimed at accelerating the delivery of effective treatments would be set, including input from scientific experts.

Recommendation 10

- ▶ To address disparities, we recommend that clinical research studies and activities aimed at translation of research findings into medical practice and to the public include specific targets for outreach to specific populations by racial/ethnic group, sex, and socioeconomic status, as well as to populations at high risk for AD (e.g., people with Down Syndrome).

Recommendation 11

- ▶ We recommend that HHS develop accurate and relevant metrics for assessing the impact of Alzheimer's on the U.S. economy.

Recommendation 12

- ▶ We recommend that HHS commit to an effort to maximize private investment in the development of treatments and improvements in disease monitoring technology by identifying policies that would encourage private industry to invest aggressively in disease-modifying interventions, to support technologies that improve our ability to detect the disease as early as possible, and monitor the disease accurately so that the effectiveness of interventions can be tested.

Recommendation 13

- ▶ We recommend that the Administration expand and enhance meaningful coordination with global partners and move forward to establish a Global Alzheimer's Action Plan to respond to the global scope of the problem.

Discussion

Research
Subcommittee Recommendations

Public Comment Period

Additional comments may be emailed to:
napa@hhs.gov