

# **RECOMMENDATIONS OF THE PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES**

The United States faces a public health crisis due to the tremendous physical, emotional, and financial costs of Alzheimer's disease and related disorders (AD). This disease severely impacts the well-being of our citizens and the economic health of this nation. An estimated 5.4 million people are living with the disease today, and it is the sixth leading cause of death. The costs to the health and long-term care systems for people with AD are estimated to be \$200 billion in 2012. Although AD can strike throughout adult life, people aged 65 and older are at highest risk. As the proportion of older adults increases dramatically over the next 20 years, it is estimated that the prevalence of AD will skyrocket to 11-16 million people by 2050, driving the cost of care to \$1.1 trillion for AD in that year alone. Given these devastating numbers, it is even more disturbing that of the top 10 causes of death, AD is the only one without a way to prevent, cure, or slow its progression. This is an intergenerational challenge, affecting all family members and creating for future generations a fiscal burden of potentially devastating impact.

Although AD research has made a number of new and important discoveries, we are still not aware of the neurobiological triggers for the changes in the brain that progressively destroy cognitive function. Furthermore, researchers have made interesting observations of associations between certain lifestyle factors and risk for disease, but have not yet discovered interventions that could delay onset of AD. In fiscal year 2012, the federal government estimates it will have committed only \$498 million at the National Institutes of Health (NIH) for AD research. This level of resource commitment falls drastically short of the funding needed to accelerate the pace of research on prevention, cures, and treatments for AD. Given the devastating health and fiscal impact of AD in the United States and globally, a creative and robust program of additional resources for AD research is not only justified but is essential to the saving of millions of lives and trillions of dollars. We know from spending on diseases like AIDS, cancer, heart disease, and diabetes that when research funding is increased, the pace of discovery and breakthroughs accelerates, resulting in treatments for those with or at risk of acquiring the disease, and eventually decreasing mortality.

Therefore, we must increase our commitment to resources for research on AD. A National Plan committed to preventing and effectively treating AD by 2025, should start with a careful evaluation of the level of resources required to achieve that goal, through research, and improvements in clinical care and planning for long-term services and supports (LTSS). However, a truly National Plan must also engage private industry, not-for-profit organizations, states, and global partners in both the development and execution of a strategic research and treatment discovery plan and the mobilization of the resources required to achieve what we hope will become, with this Administration's leadership, a global goal of preventing and effectively treating AD by 2025.

It is imperative that our health care and LTSS system becomes dementia-capable. Research to find treatments is crucial, but until we have those options there is much to do to improve the care that we offer throughout our health care and LTSS systems. One goal would be that individuals with AD have the disease detected and diagnosed at an early stage, receive assistance with care planning, and have access to coordinated and high quality health care and LTSS throughout the course of the disease. That goal drove us toward specific recommendations in detection, diagnosis, care across the stages of the disease, hospitalizations, care transitions, and developing a more robust workforce that is better trained in dementia care. We are mindful of the diverse populations and their caregivers who are affected by AD and their specific challenges, which we tried to address in our recommendations. The Advisory Council also focused on the needs of the estimated 15 million unpaid caregivers who are essential to support people with AD. This illness is unique in its societal, economic and personal toll. Improvements in clinical care and LTSS can help millions of people now, so the Advisory Council believes that the resources must be committed to make these meaningful changes.

The Plan must address the millions of people who currently have the disease, and their caregivers. AARP valued the economic impact of all caregivers at an estimated \$211 billion in 2011. This care is provided at great risk to their own health and livelihood. Unreimbursed care provides the backbone of support for people with AD. We know today that much can be done to address the needs of a person with AD, and we have evidence-based strategies to support the caregivers. Research has shown that with early detection, caregiver training and support services people with AD can continue to reside in the community, with dignity, for up to a year and a half longer than when caregivers lack training and support. This is just one example of why the plan must provide for the key elements of support of caregivers and address research related to caregivers and the impact of caregiving on them. This requires that public and private resources be coordinated to maximize impact, fill gaps, and continue to build on what works in states and communities across America. These efforts need to include health care, public health, aging and social services. As we face the growing tide of an aging America we must dramatically increase our efforts in this arena. It is not enough to increase funding for research we must also focus resources today to: identify the disease early; address symptoms and co-morbidities effectively; train and support caregivers in meaningful ways; and build the necessary public and private state and local systems to accomplish these goals.

With this as a motivation, the National Alzheimer's Project Act (NAPA) was signed into law in January 2011. A part of that legislation required the creation of the Advisory Council for Research, Care and Services (the Advisory Council), according to the Federal Advisory Committee Act, to make recommendations to the Secretary of Health and Human Services (HHS) on the development of a National Plan for AD. This Advisory Council was selected in the summer of 2011 and has been meeting to advise the Secretary on the development of the initial plan. The Advisory Council was also charged with developing a set of recommendations to the Secretary and Congress, including additional items that were not included in the plan itself. In order to meet these objectives, the Advisory Council created three subcommittees: Research, Clinical Care, and Long-Term Services and Supports.

The National Plan to Address Alzheimer's Disease is organized around five goals:

- Prevent and Effectively Treat Alzheimer's Disease by 2025;
- Optimize Care Quality and Efficiency;
- Expand Patient and Family Support;
- Enhance Public Awareness and Engagement; and
- Track Progress and Drive Improvement.

The National Plan proposes strategies to achieve each goal. Under each of these strategies, it identifies specific actions that HHS or its partners will take. HHS proposed these actions based on the current resources available for AD research, care, and LTSS.

To reach the ambitious national goal of preventing and effectively treating AD by 2025 and to meet the needs of the millions of people with AD and their caregivers, the Advisory Council believes it essential not to limit our vision to what can be achieved with existing resources. The Advisory Council believes that more aggressive action steps are needed to reach that goal and that more resources are needed than are currently available. As such, a set of recommendations reflecting the input of the Research, Clinical Care, and LTSS subcommittees has been generated and is included in this document.

The following recommendations were adopted by unanimous consent by the 11 non-federal members of the Advisory Council on April 17, 2012. We submit these recommendations for your consideration. Consistent with the National Plan and the approach used by Congress in NAPA, we use the term "Alzheimer's disease," or AD, to refer to Alzheimer's disease and related dementias.

1. **We support and applaud the goal of the National Plan -- to prevent and effectively treat AD by 2025.**
  - We recommend that interim milestones be set, through development of a clear roadmap of research and treatment discovery priorities and timelines, to assure continuing and successful progress toward achievement of this goal. For example, we recommend that an

interim milestone be set to make available to the public by 2020 significant disease-modifying or substantially-enhanced, symptom-mitigating behavioral or pharmacologic interventions.

- While these goals of making new remedies for AD available by 2020 and 2025 are ambitious, they should not be interpreted as favoring translational drug development over basic discovery. New investment in basic research and drug discovery must reflect a critical balance between long-term investment and the urgency of immediate improvements in our nation's public and fiscal health.

**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 AD research initiatives spanning basic, translational, and clinical research.**

- The Administration, working with the research and business communities, should develop an overall budget needed to achieve the 2025 goal, and should propose to Congress and support a rapid ramp up to a minimum \$2 billion in AD research funded by NIH. The optimum levels of annual funding needed to achieve the 2025 goal should be determined in connection with the preparation of the President's budget, and should be reviewed and adjusted each year based on progress and new developments.
- As part of the strategic research plan mentioned in the National Plan, we recommend that NIH develop a system of accountability to monitor progress toward the 2025 goal.
- We recommend that NIH coordinate with other federal agencies to ensure that overall federal AD funding complements the NIH's investments and enhances progress towards the goal of preventing and effectively treating AD by 2025. We also recommend that the strategic research plan identify and monitor not only existing resources within the federal government, but also new resources outside the federal government, including new public-private partnerships, incentives for increased private investment, state-based research funding, and mobilization of global investments.

**3. HHS should develop, execute and regularly update a strategic research plan and priorities to accelerate breakthroughs in AD research. In addition to research on people with the disease, the strategic research plan should also include study of caregivers of people with AD and the impacts of caregiving.**

- The process of developing that strategic research plan and accompanying priorities should be viewed as a shared project of NIH, the Food and Drug Administration (FDA), and other relevant government agencies; the academic and corporate research community; industry; and non-governmental organizations.
- Given the global scope of the challenge of AD and the international character of the research enterprise, we recommend that the strategic research plan be coordinated with the research efforts of other nations and that stakeholders from other countries with AD plans in place or in process be included in the planning process.
- The structure of the strategic research plan should be framed with the National Plan updating process in mind so that issues can be addressed not only annually, but also in synchrony with the Plan updates and so that progress can be tracked using potential convening partners for different action.
- The Director of NIH should monitor the AD research portfolio across all Institutes and Centers of NIH.

**4. To address disparities, clinical research studies and activities aimed at translation of research findings into medical practice and to the public should 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).**

- Specific recommendations for recruitment and outreach goals for diverse populations should, in our view, be integrated into planned AD research meetings/summits.

- Resources and “formulas for success” of NIH-funded Resource Centers for Minority Aging Research, Alzheimer’s Disease Research Centers, and R01 grant awards that have successfully recruited large numbers of ethnic minorities and socioeconomically diverse people for clinical aging research can, in our judgment, be leveraged to inform any future recruitment efforts taken via NAPA initiatives.
  - In our view, private and public entities can collaborate to increase diversity within clinical trial participation through existing and publically funded prevention registries producing increased identification of ethnically and socioeconomically diverse people for participation in clinical studies of AD.
5. **HHS, in partnership with the research community and industry, should take steps to accelerate public access to new therapeutic interventions by compressing the current average time for 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, including the following:**
- Convening expert advisory panels/conferences to identify genetic, family history, medical co-morbidities, biomarkers, and clinical features in asymptomatic persons that are risk or protective factors for AD neuropathological physiology and ultimately AD clinical symptoms.
  - Cataloguing existing AD biological and behavioral marker initiatives including their current development and review, and identifying gaps and a plan for addressing them.
  - Issuing, upon endpoint approval, of unambiguous guidance on the use of behavioral and biological markers to industry on their usage.
6. **The Secretary of HHS, in consultation with academic researchers, state research coordinators, not-for-profit AD organizations, and the private sector, including sponsors of investigational diagnostic and therapy trials, by the end of 2012 should 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.**
- The Secretary, in conjunction with NIH and FDA, should increase targeted public-private partnerships that bolster innovation and regulatory science progress.
7. **As part of the initiative to accelerate public access to new therapeutic interventions, the Secretary should examine and include as part of her annual report to Congress and the Advisory Council:**
- How HHS uses existing authorities to reduce drug development barriers and accelerate development of new therapies.
  - Immediate steps HHS will take to address any identified drug development barriers, including regulatory hurdles; patent, intellectual property, regulatory science, or clinical trial infrastructure weaknesses; and to advance regulatory science, guidance, and other initiatives under existing authorities.
  - 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 for innovative therapies and diagnostics.
8. **The FDA should review and periodically report to the Advisory Council:**
- Recommendations to further accelerate FDA review processes without compromising current standards of safety and efficacy.

- 9. The Secretary of HHS should develop a continuing process by which research priorities aimed at accelerating the delivery of effective treatments would be set, including input from scientific experts.**
- In our view, a joint NIH and industry working group should be established, which can serve as an opportunity to create a true partnership between government and industry to inform research priorities.
  - In order to accelerate the process of discovery, we recommend that this working group identify strategies for increasing the standardization, disclosure, pooling and analysis of pre-clinical, clinical and electronic health data.
- 10. HHS should develop accurate and relevant metrics for assessing the impact of AD on the United States economy.**
- We believe it important to develop a system of accountability for the achievement of the 2025 goal, including estimates of the impact of prevention and effective treatment of AD on the United States economy, families and costs to federal health care programs.
  - Identify and rectify the shortcomings of the data needed to assess the prevalence, costs (financial, fiscal and economic), and deaths relevant to AD, as well as the impact on caregivers and worker productivity.
- 11. HHS should 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.**
- As part of the larger NAPA agenda, we recommend that a process or mechanism for securing sustained industry input on topics such as measures to spur discovery and streamline regulatory review, tax, and intellectual property be established, with a particular emphasis on diminishing the barriers to sharing both basic scientific and clinical data, and other incentives.
  - We believe a strategic use of Small Business Innovation Research, Small Business Technology Transfer Programs and other co-investment initiatives can be used to promote advanced research and support from small businesses engaged in this work.
  - Through a joint public-private process, we believe that we can advance other related actions included under other recommendations (e.g., the industry engagement with NIH, research prioritization, behavioral and biomarker and endpoint validation, etc.) that are already known to be of importance to industry.
- 12. Expand funding and incentives for health care providers to become more knowledgeable about dementia and to encourage individuals to pursue careers in geriatric specialties.**
- Congress should increase funding for the inter-professional geriatrics education and training programs for health professions students, faculty, practitioners, direct service workers and family caregivers under Title VII and Title VIII of the Public Health Service Act.
  - Congress should increase funding for loan repayments and other incentives for those who study geriatrics and gerontology and then work in underserved communities.
  - HHS should partner with the medical, nursing, and allied health profession programs to provide geriatric education offerings in their curricula.
  - The Health Resources and Services Administration should partner with a broad array of health organizations to disseminate information to providers about AD, detection and diagnosis, dementia care throughout the disease's stages, and support systems available for affected individuals, caregivers and families.

- 13. State education and health agencies and others should include key information about AD in all curricula for any profession or career track affecting LTSS.**
  - State education agencies, other relevant state agencies, regional accrediting bodies, and professional organizations should require current information about AD be included as a condition of approval of any curriculum or course of study leading to licensure or certification.
  - Appropriate organizations should require that current information about AD be included in all relevant continuing education activity and all relevant state recertification programs.
  - First responders, state and local health and human service personnel, and others who serve the public (including staff at relevant federally-funded agencies, such as Area Agencies on Aging and Aging and Disability Resource Centers), should receive appropriate information and training regarding AD and the early warning signs of possible cognitive impairment to assure they can effectively perform their work.
  
- 14. States should ensure that Paraprofessional Caregivers in every venue are adequately trained and compensated.**
  - Mandate that paraprofessional caregivers receive at least 10 hours of dementia specific training from a reliable source.
  - Because many of these workers are working multiple shifts at below subsistence wages, often with few benefits, states should enact policies that ensure that their hours and pay reflect a fair and living wage.
  - Compensation should reflect the completion of a prescribed training program.
  
- 15. Redesign Medicare coverage and physicians' and other health care providers' reimbursement to encourage appropriate diagnosis of AD and to provide care planning to diagnosed individuals and their caregivers.**
  - Congress should pass legislation to create Medicare coverage for a package of services that covers the clinical diagnosis of AD as well as care planning for the individual and their caregivers.
  - This Medicare coverage should include care planning with a family caregiver even if the individual with the disease is not present.
  - In exchange for Medicare reimbursement for this package of services, physicians and other healthcare providers should be required to document the AD diagnosis in the individual's medical record.
  - Clarify and disseminate information to providers about the procedures under Health Insurance Portability and Accountability Act with regard to sharing medical information with caregivers related to dementia, prognosis, and care planning.
  
- 16. LTSS systems should refer to a health care provider for diagnosis whenever someone is admitted to or assessed for eligibility for LTSS and exhibits signs of cognitive impairment. Providers engaged in diagnosis should consider the 2011 guidelines for diagnosis.**
  - Whenever a person exhibits symptoms of cognitive decline, a diagnosis should be considered using the 2011 guidelines.
  - The state lead entity should assure this recommendation is included in any assessment for eligibility for LTSS.
  - Federal agencies should assure that appropriate training resources are available to health care providers on the use of the guidelines.
  
- 17. The process of diagnosis should include engaging individual and family in advance care planning (health, legal, estate, and financial).**
  - Health care providers involved in diagnosis should include advance care planning in the health care plan after discussion with the individual and family members as appropriate.
  - Health care providers should have ready access to information for referral of people diagnosed with AD and their family to community resources for financial and estate planning.

- The state lead entity for AD should assure that an inventory of community resources is maintained through appropriate state and local resources. This should be one of the activities eligible for federal funds as available.
- 18. HHS should assure that health and related systems funded with federal resources should improve chronic disease treatment and related services for people with AD.**
- People with AD often have other (multiple) chronic conditions. Treatment options for persons with AD are limited and prognosis is negatively affected when individuals have acute flare-ups related to these conditions or complications, (e.g., stroke, chronic obstructive pulmonary disease, coronary heart disease).
  - Care plans for people with AD should be tailored to their conditions, especially during recovery and rehabilitation.
  - Incorporate training for primary care providers and specialists regarding the impact of AD on care for co-morbid conditions in existing pre-service and in-service training curricula.
  - Engage professional organizations to develop tools and guidance for clinicians and social service professionals.
  - Engage professional organizations to develop tools for caregivers to assist with management of multiple chronic conditions and link to the HHS Framework to Address Multiple Chronic Conditions.
- 19. HHS should develop quality measures and indicators for the comprehensive care and treatment of individuals with AD.**
- The Agency for Healthcare Research and Quality -- in consultation with the National Quality Forum, the Institute of Medicine, and various stakeholders -- should develop quality care measures and indicators for diagnosis, treatment, and care of individuals with AD.
  - Over time, these quality measures and indicators should cover: care in various settings (e.g., physician's offices, hospitals, home care, nursing home and assisted living facilities, community services, etc.); care coordination among settings; and transitions between settings, including care coordination during such transitions.
  - The Centers for Medicare and Medicaid Services (CMS) should implement demonstration projects to study the application of dementia quality care measures and indicators as they are developed.
  - CMS should implement policies for Medicare and Medicaid to embed the quality measures and indicators in the health care system.
- 20. Assure a robust, dementia-capable system of LTSS is available in every state.**
- Every state should identify a state lead entity for AD to coordinate activity across state agencies and programs in concert with the National Plan.
  - Services should include a full array of culturally and linguistically competent and evidence-informed or evidence-based programs in individual and community settings. According to the National Council on Aging, evidence-based is *"a process of planning, implementing, and evaluating programs adapted from tested models or interventions in order to address health issues."* Evidence-based programs focus on populations -- like older adults -- emphasizing both prevention and treatment. These programs do not replicate research, or accessible LTSS for people with AD and their family caregivers.
  - Services for people with AD include: outreach; early detection; diagnostic; care and estate planning; treatment (medical, psychiatric, pharmacological and social/cognitive interventions such as memory classes); care/treatment advocacy (e.g., medication management, benefits counseling and patient navigation); early stage support services; social support services (e.g., adult day, activity of daily living supports like escorted transportation, meal preparation, home and personal care assistance, etc.) supportive housing and home safety assessment/modifications; safety services (medic-alert, safe return, GPS based programs, etc.); hospital and community-based end-of-life and palliative care.

- Services for families or caregivers include: outreach; advocacy; disease and self-care education; psycho-social support groups; supports for long distance caregivers; caregiver centered dementia care management (such as T-Care); legal and financial (including family care tax relief policies and benefits counseling) services; a continuum of respite services; and supportive workplace family care policies.
- Services should utilize innovative gap filling and financing strategies.
- CMS should provide guidance to all states on adding adult day services as a state optional service under Medicaid.
- Services should encourage development and provide LTSS linkages to state, local; and private supportive housing resources.
- Services should encourage development and implementation of dementia-capable transportation services.
- Public payments for services should reflect a living wage and recognize any special training for dementia-capable services.

**21. 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.**

- The state lead entity will be responsible for: coordinating public and private resources and programs; building capacity for epidemiology; evaluating programs and improving quality; maximizing the positive impact of services for people with AD and their caregivers; reducing duplication; coordinating public awareness; and assuring that evidence-based, high quality services are available in their state.
- HHS should identify an appropriate office or operating division to manage funds for the identification of state lead entities.
- The identified office should develop standards for the state lead entity that should be met as a condition of funding.
- Understanding that states are organized differently, standards should be flexible enough to accommodate various agencies as lead, based on what is appropriate for each state.
- Governors should be enlisted to designate the lead entity for their state, and that designation should carry authority to impact program activity across agency lines when necessary.
- States should be engaged to draft (or update) a state plan to address AD, in concert with the National Plan.
- HHS should fully fund the costs of cognitive impairment and caregiver surveillance through the Behavioral Risk Factor Surveillance System in every state.

**22. Practice recommendations for care in every setting should be embedded in CMS' federal and state surveillance and quality improvement systems.**

- Appropriate federal agencies should engage broad groups of stakeholders in the development of "best practice" guidelines for all long-term care settings (home, supportive housing, rehabilitation facilities, nursing home, and hospital).
- These guidelines should be widely disseminated.
- These guidelines should be embedded in all federal and state surveillance and quality improvement systems.
- Practice recommendations should include the appropriate management of AD and common co-morbid physical and behavioral health conditions.

**23. Recommendations for end-of-life or palliative care should be incorporated into all CMS surveillance and quality improvement systems.**

- Because at this time AD is a terminal illness marked by diminishing capacity, use of palliative care and desires regarding end-of-life care should be discussed and documented as early as practical in the disease process.



- Federal and state surveillance and quality improvement systems should all include measures assuring this communication has taken place in a meaningful way.
24. **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 AD, 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).**
- Within one year, CMMI should provide grants for medical home pilot projects specifically targeted at Medicare beneficiaries with AD.
  - Within one year, CMMI should provide grants for medical home pilot projects specifically targeted at dual eligible individuals (those seniors eligible for both Medicare and Medicaid) with AD.
  - CMS should incorporate those projects that prove successful into the system-wide Medicare program.
25. **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 CMMI to implement and evaluate the models.**
- HHS should convene a blue ribbon panel to recommend one or more models of palliative care for people with advanced dementia.
  - Such models should include the eligibility criteria for receiving such care and financing mechanisms on how to pay for it.
  - CMMI should provide grants to study the various models of palliative care recommended by the blue ribbon panel.
26. **HHS should create a specific grant round of pilot projects through CMMI to implement and evaluate ways to reduce potentially preventable emergency department visits and hospitalizations for individuals with AD, including those from home, assisted living facilities, and nursing homes.**
- Develop a public-private partnership to develop and evaluate ways to improve hospital care, care coordination, and transitions of care for people with AD, including training approaches and proposed quality measures.
  - Within one year, CMMI should create a specific grant round focused exclusively on pilot projects and demonstrations to reduce preventable hospitalizations and length of hospital stays among individuals with AD.
  - Funded projects should include at least one project that targets individuals from diverse communities.
  - The grant round should also consider funding projects aimed at reducing re-hospitalizations among those with AD by, for example, testing models of transitional care.
  - CMS should incorporate those projects that prove successful into the system-wide Medicare program.
  - Within one year, HHS should, in partnership with hospital and nursing associations, develop and evaluate ways to improve hospital care for people with AD.
  - Within one year, CMS should gather findings from Community-Based Care Transitions Programs to disseminate widely and consider policy and reimbursement changes to Medicare that would make transitions safer and less common.
27. **HHS and state lead entities should partner to assure access to the full array of LTSS for special and emerging populations of people with AD including younger people, people with intellectual disabilities such as Down syndrome, and others.**
- HHS and state lead entities should also assure supports are tailored for caregivers/family members of special and emerging populations.

- All guidelines and quality improvement efforts should include special and emerging populations.
  - Implementation efforts should be coordinated with similar efforts directed at specific populations.
  - All Older Americans Act Title III services should be made available to those with younger-onset AD.
  - The Administration on Aging (AoA) should track and report use of Title III services, especially under the National Family Caregiver Support Act, by those with younger-onset AD to assure that data is readily available on related costs for future planning.
- 28. Recommended use of federal funds (\$10.5 million) currently proposed for 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.
  - Governors 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 program should be expanded in future years with additional resources.
  - Estimated funds necessary to fully fund all states = \$85 million.
- 29. Funding for the Alzheimer’s Disease Supportive Services Program (ADSSP) should be restored to the FFY 2003 level of \$13.4 million.**
- This program supports evidence-based and promising practices in supporting people with AD and their caregivers in the community.
  - HHS, state lead entities and partners can use the lessons learned from this program to spread the availability of valuable services and should develop a long-range plan to convert ADSSP from a demonstration program to a program that provides widely-available services based on the findings from the demonstrations.
- 30. Fully fund caregiver support under AoA.**
- AoA currently has the National Family Caregiver Support Program, a component of which can be expanded to better meet the needs of caregivers of individuals with AD.
  - These improvements can result in mitigation of other system costs.
  - This program is currently dramatically underfunded and therefore unable to meet the needs of this growing population.
  - Fully funding this program can enhance other related efforts to improve quality of life for people with AD and their caregivers.
  - We recommend that program funding be doubled to move toward full funding.
- 31. 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 AD.**
- The health and well-being of a caregiver has a direct impact on the health and quality of life of a person with AD.
  - Whenever a caregiver accompanies a person with AD to a health care appointment; emergency department visit; or hospitalization, the attending health care provider should ask if the caregiver is well for the purpose of information and referral to care if needed.
  - HHS should explore adding a Health Effectiveness Data and Information Set question to assess that this is occurring.
  - Appropriate federal agencies and state lead entities should assure that the importance of this action is incorporated into training of health care providers and incorporated into education messages for the public.
  - Caregiver needs assessments should be made an explicit permitted use of federal funds by states under the National Family Caregiver Support Program.

32. **The Office of the National Coordinator, in partnership with the private sector, should assure that development of health information technology includes tools for caregivers to assist in the care of the person with AD to address dementia and multiple chronic conditions as well as maintain their own mental and physical health.**
- Caregivers should have access to reminder tools; communication methods among caregivers; home monitoring tools; and enhanced decision supports that help instill confidence and reduce isolation.
33. **HHS should launch a nationwide public awareness campaign to increase awareness and to promote early detection of AD.**
- The Centers for Disease Control (CDC) should be the lead entity, responsible for coordinating a public awareness campaign with relevant federal agencies and other stakeholders in a public-private partnership to increase awareness of AD and to promote early detection and diagnosis.
  - CDC should partner with professional groups to launch a parallel awareness campaign targeted at physicians and other health care professionals about the benefits of early detection and diagnosis of AD.
  - Both campaigns should include promotion of Medicare's Annual Wellness Visit as a vehicle for health care professionals and patients to talk about memory problems and cognitive function.
  - The campaigns should include specific efforts in diverse communities and populations, including younger-onset individuals and persons with intellectual disabilities.
  - CDC should involve state, county, and local public health departments in the campaigns and encourage them to launch public awareness and early detection campaigns of their own.
34. **The Administration should 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.**
- Moving that objective forward might start with convening a meeting of all nations or regions with National or Regional Alzheimer's Plans in place or under development by 2013 in order to compare approaches and identify mechanisms to foster global coordination and progressively address the global problem.
  - The responsibility for such an initiative would require the identification of a single high-level United States official as the point person for the National Plan and appointment of that person to represent the nation as part of an ongoing dialogue with global counterparts.
  - We believe that such a Global Alzheimer's Action Plan can be built upon existing global collaborative research initiatives and lead to greater global collaboration and coordination of research funding on a global level.
  - Any Global Alzheimer's Action Plan should foster ongoing international dialogue and potential coordination on AD regulatory review and related issues.
35. **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 the National 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.**
- The designated Office within the White House should be responsible for adequate monitoring across agencies and the designated Office within the Office of the Secretary of HHS should be responsible for monitoring within HHS.
  - We believe it important to develop a system of accountability for the achievement of the 2025 goal based on quantifiable metrics and milestones with respect to the action steps and strategies in the national plan.

- We recommend that the Secretary, as part of her annual report to Congress and the Advisory Council, report on progress over the prior year in meeting the annual objectives, strategies and actions enumerated in the National Plan, as well as provide a comprehensive, multi-year perspective, and mid-course corrective action steps, that are needed in order to meet the 2025 goal of this Plan.