

# **PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2014 Recommendations**

The initial United States National Plan to Address Alzheimer's Disease (National Plan) was released in May of 2012, and the first update of the National Plan was presented in June of 2013. The first stated goal of the National Plan is to "prevent and effectively treat Alzheimer's disease by 2025." The National Plan has resulted in significant progress being made toward the fight against Alzheimer's disease, and we are confident that the 2014 update to the National Plan will propose significant advancements beyond those in the 2013 update.

Alzheimer's disease remains a global crisis. It is estimated that over 44 million people around the world have the disease today and that by 2050 that number will be over 135 million. The cost of care for those with disease was estimated in 2010 to be over \$600 billion, one percent of global gross domestic product. The human toll of the disease and its economic impact are being felt around the world. In the face of what the National Institutes of Health (NIH) is calling an "emerging epidemic", United States leadership is crucial -- not only to the impact that Alzheimer's is having in our country but to the impact that the disease is having globally.

Recognizing the substantial national and international burden caused by Alzheimer's disease, the National Alzheimer's Project Act created the Advisory Council on Alzheimer's Research, Care, and Services, which is charged with making annual recommendations to the Secretary of the U.S. Department of Health and Human Services (HHS) and the Congress on ways to address Alzheimer's disease. The Advisory Council focuses on three overlapping areas: research, clinical care, and long-term services and supports (LTSS). Each year, the Advisory Council makes its recommendations within the context of the National Plan, and the progress made over the previous year.

## **Research**

In 2013, significant investments were made regarding research on Alzheimer's disease. In particular, new funding for Alzheimer's disease was made available by the NIH. The NIH Director, Dr. Francis Collins, released \$40M from the Office of the Director, and Dr. Richard Hodes of the National Institute on Aging (NIA) added another \$5M from the NIA budget. These funds were used to support several research efforts that had been solicited through requests for applications. These research projects included a clinical trial to evaluate therapeutics for dominantly inherited Alzheimer's disease and a clinical trial involving individuals at high risk of developing the disease by virtue of their Apolipoprotein E4 allele status. Several other projects including a Phase 1

clinical trial, a Phase II trial to evaluate a potential therapy directed at the immune system, and studies directed at pathway discovery and innovative analytical methods for identifying new therapeutic targets were supported.

Significant accomplishments in the area of genetics were also appreciated with a large international study identifying 11 new Alzheimer's disease risk genes. This work, partially supported by the NIA, suggested new processes that may influence the development of Alzheimer's disease such as pathways and synaptic function. These findings may lead to new targets for drug development aimed directly at prevention or delaying disease progression which are central to the National Plan.

Work is continuing on the development of biomarkers for the purpose of detecting Alzheimer's disease as early as possible in the disease course. Numerous studies were published documenting the putative succession of events that occurs as one develops the symptoms of Alzheimer's disease, and these biomarkers are being incorporated into new clinical trials.

The 2013 update to the National Plan and accompanying recommendations were notable for the establishment of a set of milestones to allow the tracking of progress against the disease. The staff of the NIA along with the Alzheimer's Association developed an extensive inventory of research supported by the Federal Government and established a set of milestones with timelines for accomplishment of the major goals of the National Plan. These milestones will serve as a metric for assessing the success of the National Plan.

A major report by the RAND Corporation on the cost of dementia care in the United States was released in 2013. This study documented that the costs could rise dramatically with the increasing numbers of older people in the coming decades. In addition, the investigators found that the costs of dementia care are greater than those for heart disease and cancer. These findings underscored the urgency that is embodied in the National Plan.

A research summit on Alzheimer's Disease Related Dementias took place at the NIH in May 2013. During this meeting, international experts were convened to develop a set of recommendations for studying related dementias (frontotemporal degeneration (FTD), dementia with Lewy bodies and vascular cognitive impairment along with issues concerning disparity) and a prioritization of these recommendations for implementation.

In an effort to promote the public-private partnership aspect of the National Plan, the Alzheimer's Disease Summit: The Path to 2025 was convened by the Global CEO Initiative on Alzheimer's, the New York Academy of Sciences and the NIA with the primary goal to enlist leaders from industry, academia, technology, government, finance, philanthropy and non-governmental organizations to agree on action steps to prevent or effectively treat Alzheimer's disease by 2025. A Summit Report and Strategy following the meeting set three priorities for the field: improvements in the clinical trial process designed to increase the speed and capacity of Alzheimer's trials; development

of innovative funding models to bring additional capital to Alzheimer's discovery, development and care; and the greater use of innovative technology tools and platforms, such as Big Data, to accelerate discovery and drug development.

In December 2013, the G8 Dementia Summit held in London was dedicated to a discussion of dementia and Alzheimer's disease. G8 leaders committed to the goal of preventing and effectively treating dementia by 2025, "collectively and significantly" increasing funding to achieve that goal, development of a coordinated international research plan, a review of national incentive systems for investment in Alzheimer's research, and improvement in the care delivery systems for those with dementia. United States participation supported the major goal of the National Plan to increase international collaboration in advancing United States goals. G8 leaders also scheduled three legacy workshops in 2014 to advance their commitments, including on the following topics: (1) social impact investments; (2) new care and prevention models; and (3) academia-industry partnerships. A final legacy meeting will be held at the NIH in 2015 to discuss overall progress on the G8 commitments as well as to review the progress of dementia research.

The recommendations made in the research area focus on achieving the goal of preventing or effectively treating Alzheimer's disease by 2025 by continuing the focus on the milestones towards this goal and the funding necessary to achieve these milestones. In addition, we recommend steps to accelerate access to therapeutics for Alzheimer's disease and a strong United States commitment to the priorities identified during the G8 Summit.

## **Clinical Care**

In the clinical care arena, there were efforts advanced to move our health care system towards becoming more "dementia-capable." This is a time of dizzying change in health care, with many forces changing the way we access, receive and pay for our medical care. The 2013 update to the National Plan included efforts to raise awareness about dementia and the public health challenge that it represents. Additional funding was allocated to educate health professionals so they are more clinically capable to diagnose and treat Alzheimer's disease and more knowledgeable about interventions that will improve health and function, promote quality of life, and support caregivers health.

In early 2014, the Institute of Medicine (IOM) convened an important year-long expert panel focused on improving care for those with advanced dementia. These experts will provide much needed information and guidance about how and where we can best meet the needs of this especially vulnerable group of people.

There are several ongoing large-scale demonstration projects designed to improve care for persons with dementia who are living in the community. We hope that the results from these programs can be shared broadly over the next couple of years.

These studies will look at how best to diagnose, treat, and support people with Alzheimer's disease in the new health care organizational structures and models.

There is still much to do, and the recommendations in the clinical care area strongly urge the development of goals and metrics in this space so that our national objectives are articulated and progress toward those objectives can be regularly assessed.

## **Long-Term Services and Supports**

LTSS provide the frame on which people can plan and engage day-to-day in the activities necessary for safety, care and well-being. The array of medical, as well as social, services needed -- and ability to access them -- to support individuals with Alzheimer's disease and their caregivers in communities are vast. It is increasingly clear that the health and well-being of people with dementia and their caregivers are inextricably linked to the availability of a full array of LTSS.

Progress in improving LTSS for people with Alzheimer's disease and their families and caregivers over the past year include programs to improve the dementia- capability of the system of LTSS. There have also been improvements in the inappropriate use of antipsychotic medications to restrain people with dementia in nursing facilities, as well as a number of cross-government activities to share information and optimize existing resources through partnerships.

The recommendations in the LTSS area focus on the practical aspects of life that challenge people already burdened with Alzheimer's disease. The initial National Plan and 2013 Update provided a basis for recommendations that are both broader and more specific to highlight both the needs and opportunities that exist today.

These recommendations also flow from a growing body of evidence which shows that early identification, comprehensive planning efforts (including both persons with dementia and their families) and supportive services linked to health care, all coordinated by government and private resources, have the most potential to improve quality of life and reduce unnecessary risk for both people with dementia and their caregivers.

The recommendations recognize the key role that can be carried out by states, but is currently unrealized, and call for federal leadership to advise and support states. We believe these recommendations have the greatest potential to positively impact the skyrocketing costs associated with health care and LTSS for people with Alzheimer's disease. The trajectory of Alzheimer's disease is one that usually takes many years to evolve, and, in this climate of fiscal constraint, this is an issue that calls for taking the longer view, recognizing that decisions made today will have impact on individuals and families now and for many years to come.

## Recommendations

Since 2012, the National Plan and its accompanying recommendations have catalyzed progress in the field of Alzheimer's disease and related disorders (ADRD). We look forward to further advancements as a result of the 2014 Recommendations and the 2014 Update to the National Plan.

The 2014 Recommendations from the public members of the Advisory Council for Research, Care and Services are presented below.

1. **In order to support the goal to prevent and effectively treat Alzheimer's disease by 2025, and to continue to develop a clear roadmap of research and treatment discovery priorities and timelines, we recommend that the interim research milestones first established in 2013 be evaluated and updated each year, to assure continuing and successful progress toward achievement of this goal.**
  - Interim milestones should develop and describe a continuing process by which research priorities aimed at accelerating the delivery of effective preventions and treatments are set and executed, including input from scientific experts from both academia and industry, and describing respective public and private roles reflecting the true partnership between government and industry needed to achieve our national goals.
  - The Administration should estimate the federal funding that will be required each year to successfully complete the interim milestones through completion of the 2025 research goal. Like the milestones themselves, these estimates should be revised annually, considering progress, emerging challenges and opportunities.
  - Given the fact that existing health disparities are likely to be a driving force in both the domestic and global efforts to combat Alzheimer's disease, interim milestones should prioritize specific steps to reduce disparities in access to early diagnosis, costly diagnostic procedures, and potential disease modifying treatments, and to make significant improvements in recruitment and outreach to diverse populations, by racial/ethnic group, sex, and socioeconomic status, as well as populations at high risk for Alzheimer's disease (e.g., people with Down Syndrome).
  - Interim milestones should include a plan to identify and rectify the shortcomings of the data needed to assess the prevalence, rates of diagnosis, costs (financial, fiscal and economic), and deaths relevant to Alzheimer's disease.

- While the goal of making new remedies for Alzheimer's disease available by 2025 is ambitious, it 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 progress to our nation's public and fiscal health.

**2. The urgent need for increased annual federal research funding sufficient to fund the strategic research plan reflected in the NIH milestones and to achieve the breakthroughs required to meet the 2025 goal remains a top priority. 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.**

- 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 Alzheimer's research at 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.
- We recommend that NIH coordinate with other federal agencies to ensure that overall federal Alzheimer's funding complements the NIH's investments and enhances progress towards the goal of preventing and effectively treating Alzheimer's 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 private-public partnerships, incentives for increased private investment, state-based research funding, mobilization of global investments, and any other resources that may be generated by the innovative financing mechanisms described in the Path to 2025 Summit Report.

**3. Based on the recommendations of the 2013 ADRD Research Workshop, interim milestones for achieving specific research goals for the study of ADRD (i.e., FTD, Lewy Body Dementia and vascular cognitive impairment) should be explicitly added to the National Plan.**

- This process can be initiated in the same way that data from the 2012 AD Research Summit was used to develop interim milestones for Alzheimer's disease research, by using the NINDS Council-approved, prioritized set of recommendations from the 2013 ADRD Scientific Workshop, and should include information about federal roles and responsibilities and the roles of other sectors in achieving such milestones.

- Recommendations from the ADRD Workshop should be used to develop specific set immediate (2014 - 2016), mid-term (2017 - 2020), and long-term (2021 - 2025) milestones to achieve the goal.
- We recommend that a follow-up ADRD Summit is held in 2016 in order to review and refine recommendations based on recent scientific discoveries.

**4. We recommend that HHS, in partnership with experts from 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, by:**

- Advising and supporting the development of a reformed clinical trial process to reduce the duration of Alzheimer's clinical trials by up to two years, as recommended in the Path to 2025 Summit Report.
- Provide regulatory clarity with respect to the design, conduct, and analysis of Alzheimer's disease trials (e.g., trial enrollment, endpoints, etc.), particularly in the pre-dementia stages of disease, through the finalization and discussion of a guidance document.
- Use scientifically sound regulatory mechanisms as appropriate to help expedite the approval of effective therapies for Alzheimer's disease and other dementias, including the Accelerated Approval process to potentially approve drugs for preclinical disease based on an effect on an intermediate clinical endpoint that is reasonably likely to predict ultimate clinical benefit to patients (with further post-approval studies required), granting of Fast Track status for development programs for drugs intended to treat Alzheimer's disease and other dementias, and/or granting a Breakthrough Therapy designation for development programs with compelling preliminary evidence of efficacy in these conditions.
- Actively engage in and facilitate Alzheimer's disease related public/private partnerships to formally qualify both endpoints and biomarkers to help facilitate the conduct of Alzheimer's disease trials, and help generate data standards that will help facilitate regulatory review as well as allow for the pooling of future trial data.
- Engage with patient communities and advocacy groups to help inform the regulatory decision making process.

**5. We recommend that the Administration build on the commitments issued at the G8 Dementia Summit in London on December 11, 2013, and take a leadership role in establishing a Global Alzheimer's Action Plan to respond**

**to the global scope of the Alzheimer's challenge. We recommend that this response will include, among other strategies, the following:**

- a. A coordinated international research action plan.**
- b. A coordinated clinical trial infrastructure for Alzheimer's, including linked patient registries, longitudinal studies and trial-ready patient cohorts.**
- c. A global fund to increase collectively and significantly the funding for Alzheimer's research.**
- d. A policy framework designed to provide incentives for additional investment in Alzheimer's research, including improved harmonization of national and regional regulatory regimes regarding Alzheimer's diagnostic and therapeutic products.**

- The responsibility for such an initiative would be the responsibility of the Office and officials in the White House recommended below (Recommendation 6) as well as the agencies and departments of the Administration responsible for health, foreign affairs and finance, among others. The Administration, in that regard, should consider the appointment of a Dementia Innovation Envoy with a similar charge to that appointed by the UK government.
- We urge the Administration to support, encourage and, with other governments and international bodies, cause to establish an International Advisory Council on Research, Care and Services composed of member nations from the G8, G20 and low and middle income countries and representative of the diversity of stakeholders in the Alzheimer's-serving communities. Such an International Advisory Council would provide advice and support for the effective design and execution of a Global Alzheimer's Action Plan.

**6. We recommend that the Administration designate a specific Office and officials within the White House with responsibility and accountability for effective implementation of, and timely, transparent reporting on, all aspects of the implementation of this National Plan and of the commitments made by HHS at the G8 Dementia Summit, including any global action plan as it is developed.**

- The designated Office within the White House should be responsible for the adequate and effective monitoring of the execution of the National Plan and G8 commitments across all agencies of the Federal Government, including HHS, Defense, Veterans Affairs, Indian Health Service, State and Treasury.
- These officials will develop a system of accountability for and reporting with respect to the achievement of the United States and G8 2025 goal based on quantifiable metrics and milestones with respect to the action steps and strategies in the National Plan and in follow up to the G8 commitments.

- We recommend that the designated White House official report on progress over the prior year in meeting the annual objectives, strategies and actions enumerated in the National Plan and in subsequent G8 and other international global action plans, as well as providing a comprehensive, multi-year perspective, and mid-course corrective action steps, that are needed in order to meet the 2025 goal of this National Plan.

**7. Target the dementia awareness campaign funded in the omnibus appropriations bill toward the following specific efforts: (a) recognition and diagnosis of cognitive impairment and Alzheimer’s Disease; (b) the importance of talking to a health care provider about worsening memory problems; and (c) talking with family members and health care providers about preferences for care.**

- HHS should work closely with the Centers for Disease Control and Prevention and other public and private partners on this campaign so that the message that Alzheimer’s disease is a public health issue is highlighted. A central theme should be to de-stigmatize Alzheimer’s and encourage engagement in order to promote health and quality of life. Campaign partners could help in development of messaging as well as to magnify the reach of the campaign.
- HHS should partner with medical professional groups to launch a parallel awareness campaign targeted at primary care providers about the benefits of early detection and diagnosis of Alzheimer’s disease.
- Both campaigns should emphasize key reasons for early detection, highlight the Medicare Annual Wellness Visit (AWV) as an important opportunity to discuss any concerns/issues related to cognitive function, and should begin to explain the diagnostic process. In other words, the campaign should stimulate interest AND provide information and next steps for each audience.
- The campaigns should include specific efforts in diverse communities and populations, including younger-onset individuals, persons with intellectual disabilities, and racial/ethnic groups at higher risk of developing Alzheimer’s.
- Each federal agency involved in the National Plan process should, by April 2014, identify actions it could take, alone and in partnership with private entities, to increase and improve detection of cognitive impairment and diagnosis of Alzheimer’s disease. These actions should be subject to an interagency review, prioritized, and implemented by July 2014.

**8. Evaluate the detection of cognitive impairment component of the AWV and study possible ways to improve detection and diagnosis of Alzheimer's disease.**

- We recognize that under the current billing system, it is not possible to determine how the Medicare AWV requirement to detect possible cognitive impairment is being carried out by physicians (or even if it is being carried out). However, knowing this is important in order to evaluate the effectiveness of the approach and to determine if improvements or changes need to be made in the future. Therefore, the Centers for Medicare and Medicaid Services (CMS) should survey a representative sample of primary care providers to assess whether the AWV is being undertaken, what tools are being used, what percentage of people have a positive detection, and what percentage are being referred for a full diagnostic evaluation.
- HHS should outline the current barriers to greater detection and diagnosis of Alzheimer's disease, the steps needed to increase detection and diagnosis, and set a national diagnosis rate target, as Great Britain is doing.
- Report back to the Council by the fall meeting 2014.
- Providers engaged in diagnosis should consider the most current guidelines for diagnosis of Alzheimer's disease and rule out and treat any conditions that may mimic this disease.

**9. HHS should continue to develop quality measures and indicators for the comprehensive care and treatment of individuals with Alzheimer's disease. As part of this work, HHS should establish targets and milestones for improving the clinical care for persons with Alzheimer's disease and their caregivers through the following patient-centered goals:**

- a. I was diagnosed in a timely way.**
  - b. I know what I can do to help myself and who else can help me.**
  - c. Those helping to look after me feel well supported.**
  - d. My wishes for my care are respected.**
- The Agency for Healthcare Research and Quality, National Quality Forum, and the IOM should continue to develop and implement quality care measures and indicators for diagnosis, treatment, and care of individuals with Alzheimer's disease across care settings.
  - HHS should establish national targets and milestones for: (a) timely diagnosis; (b) the provision of early care planning with options for community support services and legal/financial planning; (c) advance care planning discussions completed and documented; and (d) the number of caregivers who receive a needs assessment.

- HHS should identify data sources that could be used to measure progress toward those targets and milestones. New sources will likely need to be developed and patient/caregiver surveys need to be considered as an important source of information.
- HHS should consider partnerships with voluntary health associations and non-profit advocacy groups to develop new data sources.
- HHS agencies and operating divisions should identify initiatives and programs that can work toward the goals, the national targets and milestones and should contribute toward data collection.
- HHS should provide an initial report on progress in establishing targets and milestones to the Advisory Council by the September 2014 meeting and should include the targets and milestones in the 2015 update to the National Plan.

**10. Clarify the privacy protections under the Health Insurance Portability and Accountability Act (HIPAA) to ensure that health care providers can engage in care planning with family members of those diagnosed with Alzheimer’s disease or other dementias.**

- Within six months, HHS should issue regulations and/or guidance clarifying HIPAA’s privacy provisions with respect to communications between health care providers and family caregivers of those diagnosed with dementia.
- Such regulations/guidance should ensure that health care providers can engage in care planning with family caregivers without the presence of the diagnosed individual.
- Following the clarification of HIPAA requirements, CMS should develop appropriate billing procedures for care planning services provided to family caregivers by July 2015.

**11. Evaluate models and demonstrations of payment and care delivery reform on the quality and cost for the subpopulation of participants with Alzheimer’s disease.**

- The Center for Medicare and Medicaid Innovation (CMMI) should ask that all current studies evaluating management of multiple co-morbidities have a specific analysis of those persons with dementia. If they do not sub-analyze persons with dementia then potential strategies for management may be identified that do not succeed in this group.

- CMMI should evaluate funded payment and delivery reform models to determine separately and explicitly the impact on quality of care and costs for the subpopulation with Alzheimer's disease.
- HHS should provide grants through CMMI for medical home pilot projects specifically targeted at improving medical and chronic condition management for individuals with Alzheimer's disease, and coordination with family and community care providers in the full array of settings.
- In evaluating the impact of the tested models and interventions on individuals with Alzheimer's disease, CMMI should give priority to: (a) models aimed at reducing preventable hospitalizations, readmissions, emergency department visits, and length of hospital stays; (b) the state demonstrations on dual eligibles; (c) models targeting care transitions; (d) medical home and Independence at Home models; and (e) Accountable Care Organizations.
- Particular attention should be paid in the evaluations to effects on individuals from diverse communities.
- The evaluations should be ongoing and incorporated into the normal evaluation component of the models in general.
- CMMI should ensure that all models and demonstrations funded in the future include effective procedures to identify people with Alzheimer's disease in their samples.
- CMMI should report on its plan to evaluate the Alzheimer's disease subpopulations of its projects, including procedures for identification of people with Alzheimer's in future projects, by June 2014.

**12. Develop and set targets, strategies and milestones for ensuring a dementia-capable primary and specialty care workforce in terms of both the number of professionals needed and ensuring basic competence among health care professionals in caring for persons with Alzheimer's disease and their caregivers.**

- Given the demographic shift toward a larger older population in the United States, HHS should determine how many dementia-capable geriatric health professionals the population will require in the short term (10 years) and the longer term (25 years) -- and then set targets, strategies, and milestones for meeting this need. The targets, strategies, and milestones should focus both on how to achieve the number of professionals needed as well as how to ensure they have competency in dealing with and treating individuals with dementia.

- In developing targets, strategies and milestones, HHS should consult with medical, nursing and social work schools; residency programs; professional organizations and boards; as well as patient advocacy organizations.
- HHS should report back to the Advisory Council by the fall meeting 2014.

**13. Increase research funding to improve understanding of advanced dementia.**

- Enable Alzheimer's Disease Centers to gather more information on disease progression and caregiver issues using the existing platforms and survey instruments.
- Increase funding for intervention research to improve advanced dementia care and decision making, including family caregiver education about advanced dementia and decision support tools to align care with family/caregiver preferences.
- NIH and private funders should consider mechanisms to encourage early career investigators to initiate and/or continue pursuing research in advanced dementia as there is a critical shortage of investigators in this area.

**14. States should assure that they have robust, dementia capable LTSS systems.**

- Every state should identify a state lead entity for Alzheimer's disease to coordinate activity across state agencies and programs and work with the private sector to implement strategies in concert with the National Plan. The dementia capable systems should include a full array of LTSS that are culturally and linguistically competent and evidence-informed or evidenced-based. Services and supports should be available in individual and community settings. According to the National Council on Aging, evidenced-based programs come from "*a process of planning, implementing, and evaluating programs adapted from tested models or interventions.*"
- The array of services for people with Alzheimer's disease include -- outreach; early detection; diagnostic services; care and estate planning; treatment (medical, psychiatric, pharmacological and social/cognitive interventions; e.g., memory classes); care/treatment advocacy (e.g., medication management, benefits counseling and patient navigation); early stage support services; social support services (such as adult day services, 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 and caregivers include -- outreach; advocacy; disease and self-care education; caregiver assessment; 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.
- CMS should provide guidance to all states about how to add adult day services as a state optional service under Medicaid.
- Public and private payments for services should reflect reasonable compensation that recognizes any special training for dementia capable service providers.

**15. HHS should provide federal funds to support a state lead entity in every state and territory. This entity will facilitate development of the state's dementia capable systems, 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. HHS should use available funds to begin this process in 2014.**

- HHS should identify an appropriate office or operating division to manage funds for the program supporting the state lead entities and convene representatives of state lead entities regularly.
- The identified office should develop standards for state lead entities that should be met as a condition of funding. Understanding that states are organized differently, standards should be flexible enough to accommodate various entities 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 draft (or update) a state plan to address Alzheimer's disease, 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.

**16. HHS should engage all relevant federal agencies to include research on LTSS that addresses dementia capability in their research agendas. Topics needing further research include:**

- Culturally and linguistically appropriate interventions across settings and translation of these interventions for persons with dementia and their caregivers.
- Interventions for persons in the early stages of dementia, including those that mitigate symptoms of the disease.
- Interventions for persons with Down syndrome and other intellectual disabilities that are at high risk of acquiring dementia as they age.
- Impact of caregiving on health and quality of life of caregivers.

**17. State, local and private sector organizations should ensure that paraprofessional caregivers in every venue are adequately trained and compensated.**

- These organizations should require that paraprofessional caregivers receive sufficient training to demonstrate cultural and dementia competence from a reliable source.
- States should enact policies that ensure that their hours and pay reflect fair and reasonable compensation because many of these workers are working multiple shifts at below subsistence wages, often with few benefits and collect necessary data to assure this occurs.
- Compensation should reflect the completion of a prescribed training program.

**18. CMS should redesign Medicare coverage and physicians' and other health care providers' reimbursement to encourage appropriate diagnosis of Alzheimer's disease and to provide care planning to diagnosed individuals and their caregivers.**

- This Medicare coverage should include care planning with a family caregiver even if the individual with the disease is not present.
- The Health Resources and Services Administration and CMS should clarify and disseminate information to providers about the procedures under HIPAA with regard to sharing medical information with caregivers related to dementia, prognosis, and care planning in FFY 2013.

19. **LTSS systems should refer people to a health care provider for diagnosis whenever they are admitted to or assessed for eligibility for LTSS and exhibit signs of cognitive impairment.**
20. **The process of diagnosis should include engaging individuals and families in advance care planning (health, legal, estate, and financial).**
  - The state lead entity for Alzheimer's disease should assure that an inventory of culturally and linguistically appropriate community resources is maintained through state, local, and private resources. This should be one of the activities eligible for federal funds as available.
21. **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.**
  - People with Alzheimer's disease often have other (multiple) chronic conditions. Treatment options for persons with Alzheimer's disease are limited and prognosis is negatively affected when individuals have acute flare-ups related to their other conditions or complications, (e.g., stroke, chronic obstructive pulmonary disease, coronary heart disease). Therefore, HHS, states, and private sector plans or providers should require that care plans for people with Alzheimer's disease should be tailored to all of their conditions, especially during recovery and rehabilitation. Professional organizations should develop tools and guidance for clinicians and social service professionals. These tools should link to the HHS Framework to Address Multiple Chronic Conditions.
22. **Recommendations for end-of-life or palliative care should be incorporated into all CMS surveillance and quality improvement systems at the earliest possible time.**
  - Because at this time Alzheimer's disease is a terminal illness marked by diminishing capacity, providers should discuss and document use of palliative care and desires regarding end-of-life care as early as practical in the disease process.
23. **HHS/CMS activity should include:**
  - Convene 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.
  - Convene a panel to recommend innovative means of financing LTSS.

- 24. HHS and state lead entities should partner to assure access to the full array of LTSS for specific populations of people with Alzheimer's disease including younger people, non-traditional families, people with intellectual disabilities, such as Down syndrome, and racial and ethnic minorities who are at increased risk of acquiring Alzheimer's disease.**
- HHS and state lead entities should work with providers to assure that supports are tailored for caregivers/family members of specific populations with Alzheimer's disease.
  - All guidelines and quality improvement efforts should include specific populations.
  - Congress should amend the Older Americans Act Title III to make these services available to those with younger-onset Alzheimer's disease.
  - The Administration on Aging should track and report use of Title III services, especially under the National Family Caregiver Support Act, by those with younger-onset Alzheimer's disease to assure that data is readily available on related costs for future planning.
  - Services should include provisions for support for children and teenagers who provide supports for persons with Alzheimer's disease.
- 25. Funding for the Alzheimer's Disease Supportive Services Program (ADSSP) should be restored to the FFY 2003 level of \$13.4 million and the National Family Caregiver Support Program should be fully funded.**
- ADSSP supports essential evidenced-based and innovative practices that assist people with Alzheimer's disease 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.
- 26. HHS, state lead entities, and providers 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.**
- 27. The Office of the National Coordinator for Health Information Technology, in partnership with the private sector, should work to assure development of health information technology includes tools for caregivers. Tools could**

**assist caregivers by: helping organize care, educating them about dementia and multiple chronic conditions, use of home monitoring tools and decision supports and providing tools to help them maintain their own mental and physical health.**