

2013 RECOMMENDATIONS OF THE PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

The first U.S. National Plan to Address Alzheimer's Disease was released in May of 2012. It represents a major step forward toward accomplishing the primary goal of the Plan to "prevent and effectively treat Alzheimer's disease (AD) by 2025." As such, this represents a bold and courageous foray into AD research, clinical care, long-term services and support (LTSS).

Over five million individuals in the United States are affected by AD, and the projections are increasing at an alarming rate; so, while the Plan represents a major step forward, it is just the beginning. The human toll and economic impact of AD cannot be exaggerated, and it is time for the United States to work toward implementing the Plan as soon as possible.

Thus far, significant progress has been made through interagency cooperation at the Federal Government level. In addition, public-private partnerships have been established to garner the support of the private sector. A great deal more needs to be done, but progress is being made. The first Plan was a major step forward, but the document was meant to be fluid and will be revised annually. The Advisory Council on Alzheimer's Research, Care and Services provided advice on the first Plan and made additional recommendations to Secretary Sebelius at that time for items that could not be included but were believed to be necessary to accomplish the goal by 2025. The Advisory Council has now reassessed its recommendations from the original plan and revised them for the development of the next version of the plan in 2013.

From the research perspective, an Alzheimer's Disease Research Summit was held at the National Institutes of Health (NIH) that brought together AD research experts from around the world, to formulate recommendations for addressing the disease. New clinical trials were launched at prevention and treatment of the disease. President Obama's administration dedicated \$50M in FY12 for AD research and proposed an additional \$80M in FY13 to continue the attack on the disease. The recommendations from the Summit have been translated into funding opportunities by NIH, and the private sector is organizing a workshop in 2013 to coordinate public-private partnerships. We still do not have a complete understanding of the biologic basis of AD, however, and basic science work needs to be accelerated. Challenges remain in clinical research focused on making the diagnosis as early as possible and validating biological and cognitive markers for the disease. No new therapies have been developed and approved for AD since 2003 so significant work is needed to identify novel therapeutic targets and conduct clinical trials for new therapies.

This year's research-related recommendations continue to emphasize the importance of committing additional resources to research in order to accelerate basic discovery and

development of effective treatments. The recommendations also focus on maximizing and collaborating with private investment in research, as well as coordination of research efforts across international lines. An important emphasis in this year's recommendations was to provide further rationale for inclusion of milestones in the next version of the Plan, to describe a process of milestone development, and to offer concrete ideas for interim research milestones based on recommendations from the 2012 AD Research Summit.

Dementia impacts the management of other diseases and importantly affects how a person interacts with the health care system. The first Plan started the important ground work that we need to improve detection, diagnosis and care throughout the stages of the disease. A new website: Alzheimers.gov was launched to provide patients and caregivers more information about and resources for dealing with dementia. The Medicare Annual Wellness Visit was identified as an opportunity for physicians to detect cognitive impairment, and several reliable tools have been introduced for this purpose. Two million dollars were allotted for improving education on AD for health care providers across the country through the Geriatric Education Centers. In addition, important investigations were launched to determine more effective ways to provide care for patients with Alzheimer's in order to slow functional decline, support caregivers, and to promote better care delivery.

In our current recommendations related to clinical care we build on that groundwork to advocate for a national awareness campaign that promotes early detection and diagnosis. A unified curriculum with the latest information on diagnosis and management of AD for primary care providers is also included. While everyone hopes for more effective treatments and ultimately a cure, currently Alzheimer's is not curable and in the United States we have millions of people in the advanced stages. Few resources have been mobilized to characterize the nature of advanced dementia and identify interventions that are helpful. Therefore we recommend a summit be convened with national experts on advanced dementia to outline the important features of good care, implementation strategies, and to identify important outstanding research questions in this area. Improving care for people with dementia is critical, and we can make changes now.

LTSS provide the frame on which people can plan and engage day-to-day in the activities necessary for safety, care and well-being. As we approach the next phase in implementation of the Affordable Care Act, it is increasingly clear that the health and well-being of people with dementia and their caregivers is inextricably linked to the availability of a full array of LTSS. The initial plan provided a basis for us to make recommendations that are both broader and more specific to highlight both the need and opportunity that exists today. A growing body of evidence shows us that early identification; comprehensive planning efforts (including both persons with dementia and their families); supportive services with linkages 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. This same set of recommendations has the greatest potential to positively impact the skyrocketing

costs associated with health care and long term services and supports for these people. The trajectory of AD 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

These recommendations of the Advisory Council on Alzheimer's Research, Care, and Services reflect advancements in the field but also recognize the huge challenges that remain. As such, the following set of recommendations was adopted by unanimous consent by the 12 non-federal members of the Advisory Council on January 14, 2013. 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, and recommend that interim milestones be explicitly stated, 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.**
 - The text of the next version of the National Plan should include the outcome of the process currently underway to specify and prioritize interim milestones. Data from the International Alzheimer's Disease Research Portfolio (IADRP), and recommendations from the May 2012 Alzheimer's Disease Research Summit, private public working groups, and other scientific meetings and collaborations is being used in the first instance to set immediate (2013-2015), mid-term (2016-2020), and longer term (2021-2025) milestones to achieve the goal. Interim milestones should also include information about federal roles and responsibilities and the roles of other sectors in achieving such milestones.
 - A model of a grid with interim milestones is attached to these recommendations (Appendix A). These milestones rely on and relate to the final recommendations from the May 2012 Alzheimer's Disease Research Summit and thus represent a focused subset of potential milestones for achieving the 2025 goal. This grid is intended to be a dynamic document that will be continuously improved and refined based on the process outlined above, including input from nationally and internationally-based public and private sources.
 - While the goal of making new remedies for AD available within the next 10-12 years 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. **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.**
 - 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.
 - As part of the strategic research plan mentioned in the National Alzheimer's 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 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, and mobilization of global investments.

3. **We recommend that the Department of Health and Human Services (HHS) continue to develop, execute and regularly update a strategic research plan and priorities to accelerate breakthroughs in AD research.**
 - The process of developing that scientific research plan and accompanying priorities should be viewed as shared project of NIH, the Food and Drug Administration (FDA), and other relevant government agencies; the academic and corporate research community; industry; and NGO's.
 - Given the global scope of the Alzheimer's challenge and the international character of the research enterprise, we recommend that the strategic research plan continue to be coordinated with the research efforts of other nations and that stakeholders from other countries with Alzheimer's plans in place or in process be included in the planning process.
 - The structure of the scientific research plan should be framed with the National Alzheimer's Plan updating process in mind so that issues can be addressed not only annually, but also in synch with the plan updates so that progress can be tracked using potential convening partners for different action or convening "streams".
 - The Director of NIH should monitor the Alzheimer's research portfolio across all Institutes and Centers of the NIH.

4. **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).**
 - 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 RCMARs, ADRCs, and R01 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 open-architected prevention registries such as the Alzheimer’s Prevention Initiative, Alzheimer’s Association TrialMatch, and NIA-funded RCMARs, producing increased identification of ethnically and socioeconomically diverse people for participation in clinical studies of AD.

5. **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:**
 - 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 neuro-pathological physiology and ultimately AD clinical symptoms.
 - Continuing to catalogue existing Alzheimer’s biological and behavioral marker initiatives including their current development and review, and identify 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.
 - Examining and reporting how the HHS uses existing authorities to reduce drug development barriers and accelerate development of new therapies.
 - Reporting immediate steps the HHS will take to address any identified drug development barriers, including regulatory hurdles; patent, intellectual property, regulatory science, or clinical trial infrastructure weaknesses; and plans to advance regulatory science, guidance, and other initiatives under existing authorities.
 - Describing additional authorities or other legislative action that may be needed to accelerate development of therapies and diagnostics.
 - Taking immediate steps to shorten time from market approval to coverage decision for innovative therapies and diagnostics.

- We recommend that the FDA continue to review and periodically report to the Advisory Council recommendations to further accelerate FDA review processes without compromising current standards of safety and efficacy.
6. **We recommend that the HHS Secretary develop and describe a continuing process by which research priorities aimed at accelerating the delivery of effective treatments would be set, including input from scientific experts.**
- There are now existing models of joint academic and Industry Working Groups, which can serve as opportunities to create true partnerships between government and industry to inform research priorities.
 - In order to accelerate the process of discovery, we recommend that Working Groups identify strategies for increasing the increased standardization, disclosure, pooling and analysis of pre-clinical, clinical and electronic health data.
7. **We recommend that HHS develop accurate and relevant metrics for assessing the impact of Alzheimer’s 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.
8. **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, monitor the disease accurately so that the effectiveness of interventions can be tested, and 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.
 - 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 SBIR, STTR 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.
9. **We recommend that the Administration continue to 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.**
- Continue to meet with nations or regions with National/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 Alzheimer's Plan and appointment of that person to represent the nation as part of an ongoing dialogue with global counterparts.
 - Any Global Alzheimer's Action Plan should foster ongoing international dialogue and potential coordination on Alzheimer's regulatory review and related issues.
10. **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.**
- 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 the departments of HHS.
 - These officials will 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 Alzheimer's Plan, 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 Plan.

11. **Launch a nationwide public awareness campaign to promote early detection and diagnosis of AD.**
 - HHS should coordinate a public awareness campaign led by the Centers for Disease Control and Prevention (CDC) with relevant federal agencies and other stakeholders in a public-private partnership to increase awareness of AD and to promote early detection and diagnosis to be launched by January 2014.
 - The CDC, Health Resources and Services Administration (HRSA), and other HHS agencies should partner with medical 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 emphasize key reasons for early detection, highlight the Medicare Annual Wellness Visit 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 pique 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.
 - The CDC should involve state, county, local public health departments, and existing aging network partners in the campaigns and encourage them to launch early detection and diagnosis campaigns of their own.
 - Each federal agency involved in the National Plan process should, by January 2014, identify actions it could take, alone and in partnership with private entities, to increase and improve detection of cognitive impairment and diagnosis of AD.
 - These actions should be subject to an interagency review, prioritized, and implemented by May 2014.

12. **Gather data on the detection of possible cognitive impairment as part of the Medicare Annual Wellness Visit.**
 - The Centers for Medicare and Medicaid Services (CMS) should gather data on physician practices regarding the detection of possible cognitive impairment component of the Medicare Annual Wellness Visit.
 - Such data should include: (a) the extent to which physicians are undertaking that component of the Annual Wellness Visit; (b) what tools physicians are using to detect possible cognitive impairment; (c) the number of people with a positive detection; and (d) what further steps (including medical evaluation and diagnosis) are recommended for those with a positive detection.
 - This data collection should be annual and ongoing, but the first report on the data should be completed by November 2013.

13. **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 AD 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 2014.

14. **Develop a unified curriculum for primary care practitioners to become more knowledgeable about AD and enhance the skills necessary to deliver dementia capable care.**
 - HRSA should develop public/private partnerships with organizations representing physicians, nurses, allied health professionals, and consumers to develop, no later than July 2014, an education and training curriculum on AD for primary care practitioners.
 - Such curriculum should include the recognition of risk factors, including among specific diverse populations, and those with intellectual disabilities.
 - By July 2014, HRSA should develop delivery methods for the new curriculum, including through webinars and Continuing Medical Education (CME) sessions, and leverage opportunities for the public partners to deliver the program as well.
 - The new changes in the DSM-V should be included, as well as specific instruction on the tools to detect cognitive impairment that are suggested for the Medicare Annual Wellness Visit.

15. **Establish a pathway to implement models and demonstrations of payment and care delivery reform on the quality and cost for the subpopulation of participants with AD.**
 - The Center for Medicare and Medicaid Innovation (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 AD.
 - In evaluating the impact of the tested models and interventions on individuals with AD, 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 AD in their samples.
 - CMMI should report on its plan to evaluate the AD subpopulations of its projects, including procedures for identification of people with Alzheimer's in future projects, by September 2013.
16. **Form a blue ribbon panel of experts on advanced dementia to develop innovations in clinical care practice and quality, including palliative care, for people with advanced dementia.**
- The Office of the Assistant Secretary for Planning and Evaluation (ASPE) should appoint members of a blue ribbon panel on advanced dementia.
 - Key topics related to quality should be discussed including: management of infections/antibiotic resistance, feeding and nutrition problems, falls and injury prevention, transitional care and hospitalizations, communication and setting goals of care.
 - By December 2013, the blue ribbon panel should issue recommendations on one or more models to improve the care for those with advanced dementia, including models of palliative care and its integration into primary care services.
 - Such models should include recommendations on eligibility criteria and financing mechanisms.
 - The panel should review the research agenda for advanced dementia and prioritize areas needed immediate attention. This review should also determine whether ethical and other concerns about randomization of people with advanced dementia are creating a major barrier to research and, if so, what alternative research approaches can be used.
 - The panel recommendations should be considered for inclusion as part of the 2014 National Plan to Address Alzheimer's Disease.
 - As appropriate, HHS should provide grants through CMMI to implement and evaluate identified models.
17. **Expand funding and incentives to encourage individuals to pursue careers in geriatric specialties.**
- Congress should increase funding for the interprofessional 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 pass legislation to provide loan repayment for those who study geriatrics and gerontology.
18. **States should assure that they have robust, dementia capable LTSS systems.**
- Every state should identify a state lead entity for AD to coordinate activity across state agencies and programs and work with the private sector to implement strategies in concert with the National Alzheimer's 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 AD 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.
 - Public and private providers should utilize innovative gap filling and financing strategies.
 - CMS should provide guidance to all states about how to add 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 and private payments for services should reflect reasonable compensation that recognizes any special training for dementia capable service providers.
19. **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 2013.**
- The state lead entity will be responsible for: facilitating development of a dementia capable system, 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

efforts; and assuring that evidenced-based, high quality services are available in their state.

- 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 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.

20. **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:**

- 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.
- Translation of interventions for persons with dementia and their caregivers into culturally appropriate programs.
- Translation of interventions for persons with dementia and their caregivers into community settings.

21. **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 that current information about AD be included as a condition of approval of any curriculum or course of study leading to relevant provider 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.
- State, local, and private sector first responders, health and human service personnel, and others who serve the public 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.

22. **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 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.
 - Public and private sector compensation should reflect the completion of a prescribed training program.
 - Federal agencies should utilize every opportunity to help assure this recommendation is carried out, beginning in 2013.
23. **Congress and CMS should 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 health care providers should be required to document the AD diagnosis and any associated services provided in the individual's medical record.
 - HRSA 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.
24. **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.**
- The state lead entity should assure that this recommendation is included in any assessment for eligibility for LTSS.
25. **Providers engaged in diagnosis should consider the National Institute on Aging's 2011 guidelines for diagnosis of AD and rule out and treat any conditions that may mimic this disease.**
- Whenever a person exhibits symptoms of cognitive decline, providers should consider a diagnosis using the 2011 guidelines.
 - Federal agencies should assure that appropriate training resources are available to health care providers on the use of the guidelines.

26. **The process of diagnosis should include engaging individual and family in advance care planning (health, legal, estate, and financial).**
- Health and LTSS providers involved in diagnosis should include advance care planning in the health and LTSS care plan after discussion with the individual and family members as appropriate.
 - Health and LTSS 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, local, and private resources. This should be one of the activities eligible for federal funds as available.
27. **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 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 AD should be tailored to all of their conditions, especially during recovery and rehabilitation.
 - Providers should incorporate training regarding the impact of AD on care for comorbid conditions in existing pre-service and in-service training curricula.
 - Professional organizations should develop tools and guidance for clinicians and social service professionals.
 - Professional organizations should develop tools for caregivers, which help them with manage multiple chronic conditions. These tools should link to the HHS Framework to Address Multiple Chronic Conditions.
28. **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 the full array of medical and LTSS settings; and care coordination and transitions among settings.
 - 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 and LTSS care system.

29. **Practice recommendations for care in every setting should be embedded in CMS' federal and state surveillance and quality improvement systems.**
- Stakeholders should develop or update consensus practice recommendations for the full array of LTSS settings.
 - These guidelines should be widely disseminated and 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.
30. **Recommendations for end-of-life and palliative care should be incorporated into all CMS surveillance and quality improvement systems at the earliest possible time.**
- Because at this time AD 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.
 - Federal and state surveillance and quality improvement systems should all include measures of whether this communication has taken place in a meaningful way.
31. **HHS should provide grants through CMS' CMMI for medical home pilot projects specifically targeted at improving medical and chronic condition management for individuals with AD, and coordination with family and community care providers in the full array of settings.**
- 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 Medicare and Medicaid programs.
32. **HHS should create a specific grant round of pilot projects through CMMI to implement and evaluate ways to reduce preventable emergency department visits, hospitalizations, and length of hospital stays for individuals with AD, who are living in the full array of settings.**
- HHS, states, and the private sector should work together to develop and evaluate methods of improving hospital care, care coordination, and transitions of care for people with AD, including training approaches and proposed quality measures.
 - Within one year of formation of this partnership, CMMI should create a specific grant round focused exclusively on pilot projects and demonstrations to reduce emergency department visits, 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 Medicare and Medicaid programs, as appropriate.
 - 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.
33. **HHS and state lead entities should partner to assure access to the full array of LTSS for specific populations of people with AD 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 AD.**
- HHS and state lead entities should work with providers to assure that supports are tailored for caregivers/family members of specific populations with AD.
 - 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 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.
 - Services should include provisions for support for children and teenagers who provide supports for persons with AD.
34. **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 and state lead entities that maximize use of public and private resources to support dementia capable LTSS.
 - Governors should designate the state lead entity and commit to sharing publicly a state plan with recommendations for action.
 - State agencies and relevant partners should be included in the state action plan.
 - Legislation enacting this program should require matching funds so as to expand program impact.
 - This program should be expanded in future years with additional resources.
 - Additional funding available at HHS or other Operating Divisions in FFY 2013 and beyond should support this activity.
 - Estimated funds necessary to fully fund all states' action plans = \$85 million.

35. **Funding for the Alzheimer’s Disease Supportive Services Program (ADSSP) should be restored to the FFY 2003 level of \$13.4 million.**
- ADSSP supports essential evidenced-based and innovative practices that assist 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.
36. **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 may result in mitigation of other system costs.
 - This program is currently dramatically underfunded and therefore unable to meet the needs of this growing population of caregivers.
 - 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.
37. **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 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 services, if needed.
 - HHS should explore adding a Health Effectiveness Data and Information Set question to determine whether caregiver risk assessment is occurring.
 - Appropriate federal, state, and private sector organizations should assure that the importance of this action is incorporated into training of health and LTSS 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 Medicare, Medicaid, and the National Family Caregiver Support Program.

38. **The Office of the National Coordinator for Health Information Technology, in partnership with the private sector, should work to assure that development of health information technology includes tools that assist caregivers of persons with AD. Tools could assist caregivers by: helping them organize the care they provide, educating them about dementia and multiple chronic conditions, and providing tools to help them 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.
 - Caregiver health and wellbeing should be incorporated into electronic records.