

# **PUBLIC MEMBERS OF THE ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE AND SERVICES: 2015 Recommendations**

The Advisory Council on Research, Care and Services for the National Alzheimer's Project Act reassessed its role in attempting to accomplish the primary goal of the National Plan to Address Alzheimer's Disease, "To prevent and effectively treat Alzheimer's Disease by 2025." The Advisory Council empanelled a work group to assess progress and several suggestions were made and the Advisory Council is acting upon them.

## **Research**

In 2014, there was increased, bipartisan recognition that more resources are needed to support the goal to prevent and effectively treat Alzheimer's by 2025. However, the Advisory Council's Research Subcommittee believes that Alzheimer's research continues to be drastically underfunded considering the societal burden of this disease and the preparedness of the scientific community to act. The passage of the Alzheimer's Accountability Act in 2014 provides a means to increase resources needed to achieve the 2025 goal. The professional judgment budget that NIH is now required to produce should reflect bold, forward-looking recommendations and milestones, which identify the total science-driven funding needs for the budget year and those anticipated through 2025. The 2013 G8 Dementia Summit initiated a growing international momentum for a global response to the challenge of Alzheimer's. The subcommittee urges the Administration and Congress to clearly articulate the United States leadership role at the international level and accordingly step up its level of commitment and senior political participation in global Alzheimer's and dementia meetings.

## **Clinical Care**

The Clinical Care subcommittee's recommendations highlight the growth in Dementia Friendly Community (DFC) efforts around the country, which are an exciting development and should be encouraged and supported. More work is needed on what patient centered quality measures can be implemented which will guide improved clinical care for this important group of people. The subcommittee also acknowledges the important studies on new models of care for persons with dementia that are ongoing at several sites. They look forward to those results and hope they can guide further improvements in our care system in the next few years. Finally, the expert panel on Advanced Dementia hosted by the Institute of Medicine concluded this year with important findings and recommendations, which affect both the Clinical Care and Long-Term Services and Supports subcommittees. The overall recommendation from this

series of panels was to ensure the quality of life and quality of care for persons living with advanced dementia and their families across care settings.

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

The Long-Term Services and Supports subcommittee recommendations, designed to complement the other subcommittees, call for support of state efforts to assess needs and address Alzheimer's disease and related dementias in a comprehensive way. A substantial portion of our population will require long-term services and supports in their lifetime and most state systems are not adequately prepared to address these needs. The subcommittee further calls for recognition of the importance of consistent quality improvements in service to persons with dementia and importantly their caregivers. This approach to dementia capability along with caregiver support, coverage, and requisite fiscal support will go a long way to meet the needs of populations impacted by this disease.

## **Recommendations**

Since 2012, the National Plan and its accompanying recommendations have catalyzed progress in the field of Alzheimer's disease and related disorders. We look forward to further advancements as a result of the 2015 Recommendations and the 2015 Update to the National Plan.

The 2015 Recommendations from the public members of the Advisory Council for Research, Care and Services are presented below:

**1. The 2015 National Plan must provide a robust, comprehensive, and transformative scientific roadmap for achieving the goal of preventing and effectively treating Alzheimer's Disease by 2025.**

- Roadmap should invite broad and inclusive input from experts.
- Priorities and interim milestones should be evaluated and updated each year.
- Include specific research milestones to:
  - Reduce racial/ethnic/socioeconomic disparities in Alzheimer's disease and related disorders.
  - Increase access to early diagnosis, diagnostic procedures, and potential disease modifying treatments among diverse groups.
  - Make significant improvements in research recruitment rates and outreach among diverse populations.
  - Include and prioritize specific milestones for Alzheimer's disease and related disorders.

- Include and prioritize specific milestones for populations at high risk for Alzheimer's disease and related disorders (e.g., people with Down syndrome).

**2. The urgent need for increased annual federal research funding sufficient to meet the 2025 goal remains a top priority.**

- Initial estimates of that level are \$2 billion per year but may be more. This investment would be applied to Alzheimer's research initiatives spanning basic, translational and clinical research.

**3. In developing their professional judgment budget, the NIH should identify the total science-driven funding needs for the budget year and also address the scale of needs anticipated through 2025.**

**4. The 2015 National Plan should outline specific contributions being made by the United States government to the international initiatives needed to fulfill the commitments made by the United States government at the 2013 Dementia Summit in London.**

- This includes how the United States government intends to raise the level of engagement, and seniority of governmental officials, engaged in those efforts.

**5. Dementia Friendly Communities.**

*The U.S. Department of Health and Human Services (HHS) should encourage efforts to foster DFCs:*

- A DFC resource currently exists on a state basis in Minnesota (Act on Alzheimer's), which has enabled 33 communities to start local efforts to better support people living with dementia and their care partners.
  - Early results from this effort has shown increased awareness of dementia throughout all sectors of the community (law enforcement, businesses, transportation, faith communities, etc.), as well as increased options for care partner support and engagement with the community.
- HHS should support a piloting process of 10-15 communities or states funded by a Request for Proposal process that would help seed community efforts and evaluate results. The communities chosen should reflect differences in cultural groups, size of community, and rural/urban locales.
- Should the evaluation of the pilot programs justify replication, then the goal would be widespread adoption of DFCs by 2020.

## 6. Improving Clinical Care for Persons Living with Dementia.

*Evaluate feasibility of measuring care quality and effectiveness by using patient centered goals:*

- HHS should identify measures currently available that would reflect patient perspectives on care satisfaction in various settings.
- Initiate regular measurement and reporting with those that are feasible now.
- Develop a specific plan to improve measurement capability over the next 3 years so that the perspectives and goals of persons with Alzheimer's and their families are known. Subsequently, the metrics/goals relating to satisfaction with care and timely diagnosis can be developed and also measured.

## 7. Ensuring the Quality of Life And Quality of Care for Persons Living with Advanced Dementia and Their Families Across Care Settings.

- Ensure access to high quality palliative care for persons with advanced dementia and their families across all settings.
- Prepare a workforce that is competent to deliver care to persons with advanced dementia and their families.
- Incentivize documentation and tracking of level of functional and cognitive status to identify people with advanced dementia.
- Support research, evaluation and dissemination of models of care to meet the needs of persons with advanced dementia and their families.
- Leverage existing mechanisms to ensure access to high quality care for persons with advanced dementia and their families.
- Support quality metrics that ensure transparency and accountability for the care of persons with advanced dementia and their families.

## 8. Dementia-Capable Long-Term Services and Supports.

*HHS should support state initiatives to provide robust, dementia capable long-term services and supports systems through:*

- Providing coordinated Alzheimer's disease related activities across state agencies through an identified state lead entity with adequate funding from Congress.

- Supporting Alzheimer’s Advisory Council partnerships with national partners to engage state governments in long-term services and supports efforts.
- Partnering with state lead entities to assure full access to long-term services and supports for populations at high-risk for Alzheimer’s disease.

**9. Long-Term Services and Supports Research and Evaluation.**

*HHS should encourage federal agencies to include research on long-term services and supports that addresses dementia capability in their research agendas. Topics needing further research include:*

- Interventions that are: Culturally appropriate, for persons in the early stages of dementia, for persons with Down syndrome and other intellectual disabilities, and for persons in the end stages of dementia.
- Impact of caregiving on health and quality of life of caregivers.
- Adequate training for paraprofessional caregivers in every venue to address cultural and dementia competence.

**10. Coverage.**

*The HHS Centers for Medicare and Medicaid Services (CMS) should redesign Medicare coverage and health care providers’ reimbursement to encourage diagnosis, support care planning, and active referral to long-term services and supports:*

- Include care planning with a family caregiver in Medicare coverage even if the individual with Alzheimer’s disease is not present.
- Incorporate recommendations for palliative care into CMS surveillance and quality improvement systems.
- Provide reimbursement for providers to discuss palliative care early in the disease process.

## **11. Caregiver Support.**

*HHS, state lead entities, and providers should assure that caregiver health and behavioral health risk is assessed and addressed regularly through:*

- Engaging individuals and families in advance care planning (health, legal, estate, and financial).
- Assuring that health and related systems funded with federal resources improve chronic disease treatment and related services for people with Alzheimer's disease as well as family caregivers.

## **12. Funding for Long-Term Services and Supports.**

*Congress should assure adequate funding for the following:*

- Activities listed in the Public Health Roadmap, the Alzheimer's Disease Supportive Services Program and the National Family Caregiver Support Program.
- The Older Americans Act Title III to expand services to people with younger-onset dementia.
- The cost of federal support for state lead entities is estimated at \$80 million. Cost of other recommendations should be calculated by public and private entities with resources to establish estimates.
- An HHS panel to recommend innovative means of financing long-term services and supports.