



The Healthy Brain Initiative

**The Public Health Road Map for State
and National Partnerships, 2013–2018**

alzheimer's 
association



The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018

Table of Contents

I Healthy Brain Initiative	1
II Action Items	15
III Conceptual Framework	39
IV Applied Research and Translation	51
Appendix A: Committees and Contributors	55
Appendix B: References	56

The Alzheimer's Association and the Centers for Disease Control and Prevention's (CDC) Healthy Aging Program have developed the second in a series of road maps to advance cognitive health as a vital, integral component of public health. *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018*, outlines how state and local public health agencies and their partners can promote cognitive functioning, address cognitive impairment for individuals living in the community, and help meet the needs of care partners. Specific actions are addressed in four traditional domains of public health: monitor and evaluate, educate and empower the nation, develop policy and mobilize partnerships, and assure a competent workforce. Public health agencies and private, non-profit, and governmental partners at the national, state, and local levels are encouraged to work together on those actions that best fit their missions, needs, interests, and capabilities.



I
Healthy Brain
Initiative

II
Action
Items

III
Conceptual
Framework

IV
Applied Research
and Translation

Healthy Brain Initiative

A Public Health Crisis

Dementias, including Alzheimer's disease

- In 2013, an estimated 5 million Americans aged 65 and older have Alzheimer's disease (Hebert, Weuve, Scherr & Evans, 2013). By 2050, unless more effective ways to prevent and treat the disease are identified and implemented, the prevalence may triple to as high as 13.8 million people (Hebert et al., 2013).
- Aging is the best known risk factor for developing Alzheimer's disease. The likelihood of developing Alzheimer's doubles about every five years after age 65 (Hebert et al., 1995).
- Alzheimer's disease is now the 6th leading cause of death and 5th among adults 65–85 years of age (Xu, Kochanek, Sherry, Murphy & Tejada-Vera, 2010).

Healthy Brain Initiative



- In 2010, the direct and indirect costs of dementia among those aged 70 and over totaled an estimated \$159 billion to \$215 billion (depending upon the monetary value placed on informal care). The direct healthcare expenditures were significantly higher than cancer and similar to heart disease (Hurd, Martorell, Delavande, Mullen & Langa, 2013). In 2013, total direct payments for all healthcare, long-term care, and hospice services incurred by those aged 65 years and older with Alzheimer's and other dementias are estimated to be \$203 billion (Thies & Bleiler, 2013). The growing demand for care poses challenges to the healthcare workforce (IOM, 2008), and economic strain on Medicare and Medicaid programs as the major funders of this care (USDHHS, 2012).

Cognitive decline

- One in eight adults aged 60 and older (12.7%) report experiencing “confusion or memory loss that is happening more often or is getting worse” over the past 12 months (Centers for Disease Control and Prevention [CDC], 2013).
- Among these individuals, only 19.3% reported discussing these changes with a healthcare provider, and 35.2% reported difficulties due to confusion or memory loss. Additionally, 34.5% live alone (CDC, 2013). Changes in cognitive abilities affect individuals differently and can gradually compromise an individual's ability to care for themselves; conduct necessary activities of daily living, such as meal preparation and money management; and effectively manage medications and existing medical conditions (Wagster, King, Resnick & Rapp, 2012).



What is cognition?

Cognition can be viewed along a continuum—from optimal functioning to mild cognitive impairment to Alzheimer’s disease and severe dementia—and may include tasks involved with cognitive function such as: language, thought, memory, executive function (the ability to plan and carry out tasks), judgment, attention, perception, remembered skills such as driving, and the ability to live a purposeful life.

What is cognitive impairment?

When cognitive abilities are impaired (often referred to as cognitive impairment), a person has trouble with cognitive processes that begin to affect the things he or she can do in everyday life. Dementia is not a disease itself, but rather a syndrome defined by a group of symptoms that often occur together in various combinations and severity. Alzheimer’s disease is the most common cause of dementia and along with other conditions such as stroke and traumatic brain injury can result in impairment in cognitive abilities. It is important to note that some causes of cognitive impairment are related to treatable health issues (e.g., medication side effects, vitamin B12 deficiency, and depression).

Healthy Brain Initiative



Impact at Multiple Levels

On individuals

Although the majority of Americans live without cognitive impairment, they often feel uninformed and fearful of the disease. According to a recent public opinion poll, 44% of Americans fear Alzheimer's disease more than any other disease, including cancer (Marist Poll, 2012). About 75% of adults report not being knowledgeable about the disease (Anderson, Day, Beard, Reed & Wu, 2009). Additionally, several reports documented a great deal of concern about the disease, both from a personal perspective and the potential of caring for someone who may develop the disease in the future. Most concerns focus on memory loss: 73% of adults are concerned or very concerned about the possibility that their memory may worsen with age (Friedman et al., 2013).

Furthermore, people with dementia report being afraid of the reactions of others and a lower perceived status within society because of the diagnosis (Katsuno, 2005). The stigma associated with dementia may promote social exclusion, a reluctance to seek help (Link & Phelan, 1999; Corrigan, 2004), a sense of shame and inadequacy, and low self-esteem (Batsch & Mittelman, 2012).

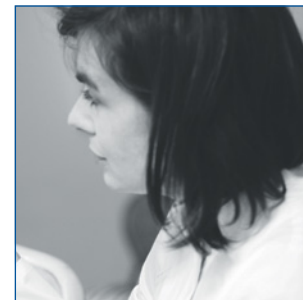
On families

Family members have traditionally been responsible for the caregiving of individuals with Alzheimer's and other dementias. The vast majority (80%) of care partners are family members in home settings (IOM, 2008). As lifespans lengthen and the population ages, a corresponding increase is expected in the number of individuals providing care, the length of time spent caregiving, and the breadth of required tasks (Schulz & Martire, 2004).

“Productivity, independence, and quality of life for millions of Americans depend on the nation’s collective ability to prevent and treat cognitive impairment and dementia, and to promote cognitive functioning for individuals living in our communities. To accelerate efforts to meet these goals and help incorporate cognitive health in the plans and initiatives of states, territories, and communities in the U.S., we look forward to working with our partners to implement the actions identified in *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018.*”

Lynda A. Anderson, PhD, and Robert Egge
Co-chairs of Leadership Committee

Healthy Brain Initiative



Care partners of individuals with dementia spend much more time providing care than care partners of individuals with other conditions. The average length of time caregivers report providing care is 4.6 years (National Alliance for Caregiving & AARP, 2009), but in the case of dementia, caregiving may range from 4 to 20 years. In 2011, over 15 million Americans spent an average of 21.9 hours per week caring for a family member with dementia—a total of 17.5 billion hours at a value of \$216 billion dollars (Thies & Bleiler, 2013).

While family care partners typically assume their responsibilities willingly (Family Caregiver Alliance, 2006), the demands of caregiving can take a toll on their health, compromising their ability to care for themselves and their family members. Family care partners of individuals with dementia are at greater risk for anxiety, depression, and poorer quality of life than care partners of individuals with other conditions (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999; Pinguart & Sörensen, 2007). Between 28% and 55% have depression, compared with 15% in the non-caregiving older adult population (Elliott, Burgio & Decoster, 2010).

On healthcare professionals

The public health workforce is large and diverse ranging from physician specialists to community health workers (Frank & Weiss, 2012). They are an important source of information and can play a critical role in caring for someone with cognitive impairment (USDHHS, 2012) as well as in attending to the needs and health of care partners as they cope with the physical and emotional impact of their responsibilities (Talley & Crews, 2007). Yet only 19% of people aged 60 and older who reported worsening confusion or memory loss have discussed their symptoms with a healthcare provider (CDC, 2013).

Among those living in the community, approximately two-thirds of the people who meet the diagnostic criteria for Alzheimer's disease or other dementias have not received a diagnosis (Boustani, Peterson, Hanson, Harris, & Lohr, 2003). Although there are no disease-modifying therapies, studies have shown consistently that active management can significantly improve quality of life through all stages of the disease for individuals with dementia and their care partners (Vickrey et al., 2006; Voisin & Vellas, 2009; Grossberg et al., 2010; Blendon et al., 2012).



Caregiving

Care for people with dementia, such as Alzheimer's disease, is often provided in the home by family members or friends. These caregivers typically have a longer and harder caregiving journey than caregivers for people with other conditions. While they provide a tremendous service to the person with dementia and to society, they are at greater risk for developing health problems.



Family Partners

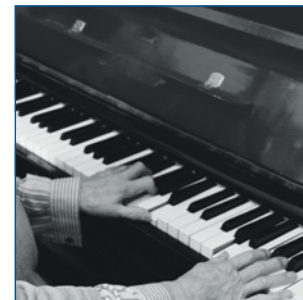
The vast majority of caregivers for people with dementia, such as Alzheimer's disease, **are family members in home settings.**



Risks of Caregiving

Caregivers of people with Alzheimer's disease are **at greater risk for anxiety, depression, and poorer quality of life** compared to caregivers of people with other chronic conditions.

Healthy Brain Initiative



National Response

The National Alzheimer's Project Act (NAPA) was signed into law on January 4, 2011. Passed unanimously in both the Senate and House of Representatives, NAPA (Public Law 111-375) calls for a national strategic plan among federal agencies to address and overcome the rapidly escalating crisis of Alzheimer's disease. The first National Plan to Address Alzheimer's Disease, released in May 2012, recognizes Alzheimer's disease as a major public health issue; provides a blueprint for coordinating Alzheimer's disease efforts across the federal government; and outlines concrete goals, strategies, and actions for eliminating the burden of the disease. Additionally, NAPA and the National Plan are generating numerous activities on the part of multiple stakeholders. The Advisory Council on Alzheimer's Research, Care, and Services monitors implementation of the National Plan and recommends changes for annual updates of its activities (USDHHS, 2012).

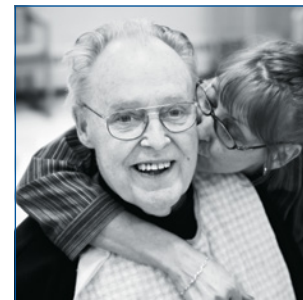
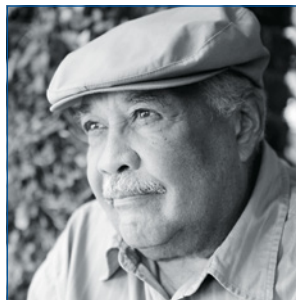
Origin of the Healthy Brain Initiative

Supported by a congressional appropriation beginning in fiscal year 2005, the Centers for Disease Control and Prevention (CDC) established the Alzheimer's-specific segment of CDC's Healthy Aging Program, referred to as The Healthy Brain Initiative. CDC partnered with the Alzheimer's Association and together they engaged other groups, including the National Institute on Aging at the National Institutes of Health (NIH), Administration on Aging (now within the Administration for Community Living), AARP, and other public and private sector organizations to launch the activities of The Healthy Brain Initiative. Together, these organizations embarked on a deliberative 18-month process to create a road map to guide a coordinated public health response across agencies and organizations. *The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health* (CDC & Alzheimer's Association, 2007) offered a "synergistic" model for moving science into practice based on several principles: a firm grounding in science, an emphasis on primary prevention, a community and population approach, and a commitment to eliminating disparities (CDC & Alzheimer's Association, 2007).



The overall intent of the Healthy Brain Initiative is to better understand the public health burden of cognitive impairment through surveillance; build a strong evidence base for policy, communication, and programmatic interventions for improving cognitive health; and translate that foundation into effective public health practice in states and communities.

Healthy Brain Initiative



The Road Map (2007) served as a catalyst for numerous accomplishments on the part of multiple stakeholders (CDC, 2011c). Successes included the national recognition of cognitive health as a public health issue by its inclusion, for the first time, as a new topic area of, “Dementias, including Alzheimer’s disease” in Healthy People 2020. This 10-year set of national objectives for improving the health of all Americans cites the goal of the new topic area to “reduce the morbidity and costs associated with, and maintain or enhance the quality of life for, persons with dementia, including Alzheimer’s disease” (USDHHS, 2013a). This topic area currently consists of two developmental¹ objectives—

- To increase the proportion of persons with diagnosed Alzheimer’s disease and other dementias, or their caregiver, who are aware of the diagnosis.
- To reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer’s disease and other dementias (USDHHS, 2013a).

¹Developmental objectives currently do not have national baseline data and, therefore, have abbreviated or no operational definitions.

Additionally, three of the objectives in the new topic area, Older Adults, also address issues of importance to this population:

- To reduce the proportion of older adults who have moderate to severe functional limitations.
- To increase the proportion of older adults with reduced physical or cognitive function who engage in light, moderate, or vigorous leisure-time physical activities.
- To reduce the proportion of unpaid caregivers of older adults who report an unmet need for caregiver support services (developmental) (USDHSS, 2013b).



Using this Road Map: State and Local Focus

Given the need to update the Road Map and the release of the National Plan in 2012, the Alzheimer’s Association and CDC agreed to revisit the Road Map with a specific focus on the role and contribution of state and local public health agencies. While federal agencies play a critical role in leading and funding efforts to address Alzheimer’s disease, state and local agencies organize and provide public health services on the ground level. For example, state agencies are critical to the development and implementation of strategic plans and services tailored to the needs of their states and local communities. Although there is considerable variation in structure and organization, each state has a department of health. State and local public health agencies with their vast network of partners play a critical role in protecting and improving the health of communities through education, organized interventions, tracking and monitoring health of populations, and research on chronic conditions and injury prevention.

The initial challenge in creating a Road Map that would speak to state and local public health professionals and their partners was how best to engage the broad public health community to apply its traditional core functions—assessment, policy development, and assurance—to facilitate the inclusion of cognitive health within priority domains of public health. The Alzheimer’s Association and CDC also wished to explore how public health could complement and facilitate the work of its key partners, enhancing the synergy of investments for even greater national impact.

Guided by a Leadership Committee, an extensive concept mapping process was used to engage a wide array of stakeholders at national, state, and community levels—including content experts, practitioners, and decision makers across the nation. Input was solicited on how state and local public health and their partners could promote cognitive functioning, address cognitive impairment for individuals living in the community, and help meet the needs of care partners. Results were used to identify the set

Healthy Brain Initiative



of strategic actions that comprise *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018*.

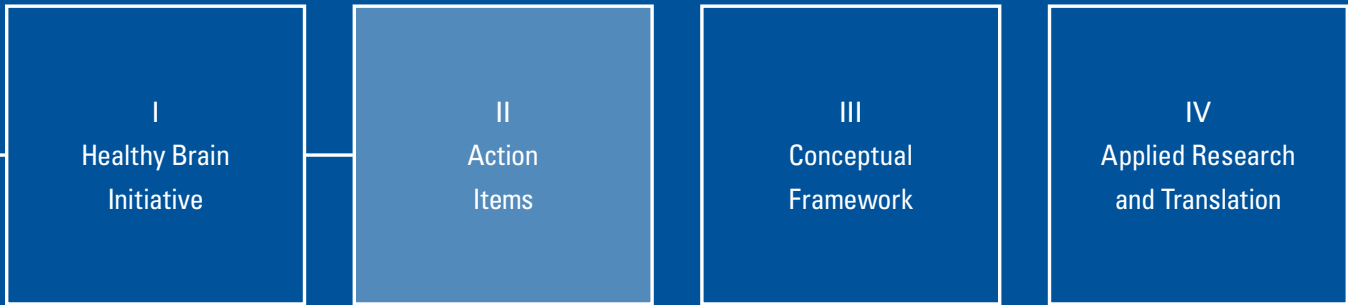
Public health takes a broad view of, and seeks to achieve lasting change in, the health of entire populations, extending beyond the medical treatment of individual people. Thus, the Road Map’s strategies are expansive in scope and recognize that it takes effective partnerships at many levels to achieve meaningful outcomes. Its developers recognize the vital contributions of private, non-profit, and governmental partners at the national, state, and local levels to address and promote cognitive functioning and the needs of care partners, and to embrace areas where synergistic opportunities exist.

Section II of the Road Map identifies specific action items that state and local public health could do—on their own or with other national, state, and local partners—and is designed to enable agencies to choose actions that best fit their needs, capabilities, and resources. The actions are grouped into four domains of activity: Monitor and Evaluate; Educate and Empower the Nation; Develop Policy and Mobilize Partnerships; and Assure a Competent Workforce.



The Healthy Brain Initiative envisions a nation in which the public embraces cognitive health as a vital component of health and is committed to its inclusion in public health efforts. To achieve that vision, the long-term goal is to maintain or improve the cognitive performance of all adults.





Action Items

Public health seeks to achieve lasting change in the health of entire populations. Thus, the Healthy Brain Initiative envisions a nation in which the public embraces cognitive health as a vital component of health and is committed to its inclusion in public health efforts. *The Public Health Road Map for State and National Partnerships, 2013–2018* lays out a spectrum of broad actions designed to promote cognitive functioning and address the needs of care partners for pursuit over the next 5 years. The actions are intended as a guide for what state and local public health could do—on their own or with other national, state, and local partners.

Agencies are encouraged to select those actions that best fit state and local needs and customize them to match priorities, capabilities, and resources.

The actions are grouped into four domains:

- Monitor and Evaluate
- Educate and Empower the Nation
- Develop Policy and Mobilize Partnerships
- Assure a Competent Workforce.

Action Items



The domains are consistent with the core public health functions of assessment, assurance, and policy development (IOM, 1988) and aligned with the Essential Services of Public Health (USDHHS, 1997). They are interdependent and essential to help ensure desired results. The process for identifying the domains and action items is detailed in Section III.

Within each domain are specific action items. All items are deemed important and are not listed in any order of priority. Within each domain, however, one or more actions are bolded because they were judged by the Leadership Committee to be issues of particular importance and areas in which movement could be achieved in the near term by groups new to this topic. Some best practices and supplementary Web sites are also provided.

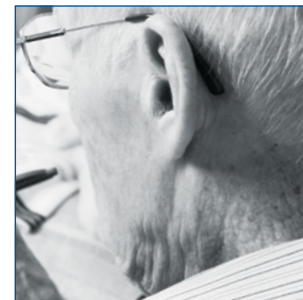
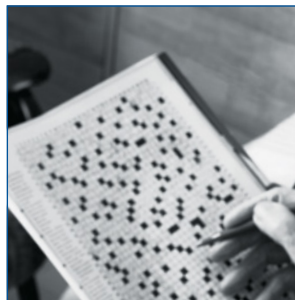
The long-term goal of the Healthy Brain Initiative, to maintain or improve the cognitive performance of all adults, can only be achieved through collaborative and effective partnerships at national, state, and local levels. The coordination of contributions by private, non-profit, and governmental partners may provide leverage for synergistic opportunities, and more comprehensively address and promote cognitive functioning and the needs of care partners. Thus, the Road Map does not focus on any individual agency or entity but instead encourages groups to work collaboratively to use and incorporate the action items into their own strategic planning efforts.

“We applaud the creation of a Road Map that promotes partnerships with states and communities across the U.S. This helps to ensure critical linkages at the national, state, and community levels which are vital to the success of our National Plan to Address Alzheimer’s Disease.”

Helen Lamont, PhD
*U.S. Department of Health and Human Services,
Office of the Assistant Secretary for Planning
and Evaluation*



Action Items



Monitor and Evaluate

Surveillance, defined as the “ongoing, systematic collection, analysis, and interpretation of health-related data,” is a fundamental tool of public health. Its methodologies have been applied for decades to numerous causes of disease, injury, disability, and death. Incorporating measures concerning cognition and caregiving into existing surveillance can help understand the public health burden, inform public health policy and strategies, and monitor progress toward promoting quality of life.

- M-01** Implement the Behavioral Risk Factor Surveillance System’s cognitive impairment and caregiver modules.
- M-02** Use surveillance data to enhance awareness and action in public health programming (e.g., link Behavioral Risk Factor Surveillance System questions on cognition to health-related quality of life or falls prevention).
- M-03** Determine key questions concerning cognition for inclusion in the National Health Interview Survey and other relevant national datasets by conducting a national-level review and promoting their use.
- M-04** Engage national organizations and agencies to develop standardized questions that can be used at the national, state, and local levels to track awareness and perceptions about cognitive health and impairment, including decline in cognitive functioning.



Increased Ability to Track the Public Health Burden of Cognitive Decline

A priority action from *The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health* (2007) called for tracking the public health burden of cognitive decline through existing surveillance systems. Today, thanks to partnerships at the state and national levels, a cognitive impairment optional module is now part of the **Behavioral Risk Factor Surveillance System**. The module provides states and territories with the ability to collect state-specific data on self-reported cognitive decline. To date, 45 states plus the District of Columbia and Puerto Rico have included the questions in their **BRFSS surveys during 2011–2013**.

The Alzheimer's Association and CDC convened a diverse panel of experts to help inform the content and design of the module, which includes 10 questions that seek information about self-reported cognitive decline and burden. Through partnerships with the state health departments' BRFSS Programs, the Alzheimer's Association's local chapters, and the aging services network, the module was disseminated and supported by numerous states.

Current efforts focus on disseminating the data through various channels, such as state data briefs, manuscripts, interactive Web sites, briefings, and presentations. With this information, state planners and decision-makers can examine the burden of cognitive decline in their states and gain insights about current and future needs.

Action Items



“Monitoring and evaluation are key practices of public health. The tools we traditionally have applied to physical health are equally valuable to understand the impact of cognitive impairment.”

Jill Myers Gadelmann, BS, RN
Bureau Chief, Chronic Disease Prevention and Management, Iowa Department of Public Health

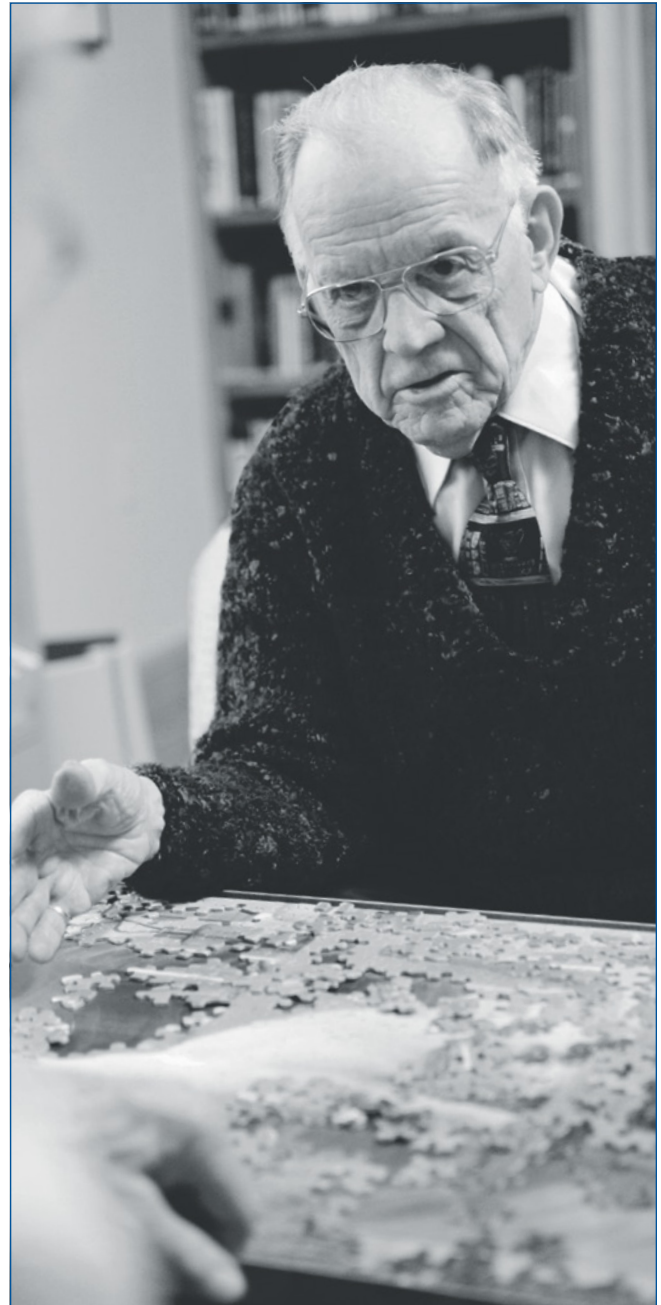
At the same time that surveillance is conducted and suitable measures of cognitive health for public health surveillance are developed or refined, the effects of cognitive impairment on economic and social systems need to be monitored. Assessments can help clarify the cost burden to states and communities as well as the important health inequities affecting the lives of people with cognitive impairment and their care partners.

M-05 Assess information about the economic impact of dementia, including Alzheimer’s disease, on states and communities and disseminate the findings.

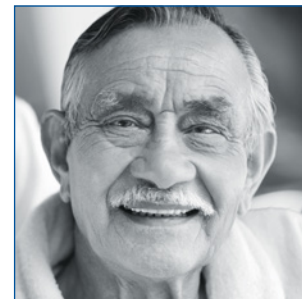
M-06 Support state and local needs assessments to identify racial/ethnic; lesbian, gay, bisexual, and transgender; socioeconomic; and geographic disparities related to cognitive health and impairment and help ensure materials are culturally appropriate.

Understanding Public Views About Cognitive Health and Dementia

Perceptions about health, including perceptions about cognitive health and impairment, affect the way individuals understand and respond to health messages. The **CDC Healthy Aging Research Network** has been reaching out to older adults and healthcare providers, using focus group methods to better understand perceptions about cognitive health and impairment in diverse groups. They have conducted 55 focus groups with over 450 participants from 9 states and found **several lessons**. First, messages about cognitive health need to be aligned with perceptions about healthy aging or “aging well.” Second, messages must be sensitive to diverse cultural views to make them more salient. A special issue of **The Gerontologist**, Promoting Cognitive Health in Diverse Populations of Older Adults, published in 2009, shared the results of this formative research.



Action Items



Research has focused on the needs of individuals with cognitive impairment and their care partners as well as the effectiveness of various interventions on their health and quality of life. That wealth of information continues to be a critical resource for the developing evidence base for intervention. Updated systematic reviews that analyze available research and practice information and disseminate conclusions are invaluable for public health use in designing effective programs and policies.

- M-07** Conduct a review of the literature on co-occurring chronic conditions and dementia, including Alzheimer’s disease, to understand the effect of dementia on various outcomes such as depression, disease management, morbidity, and mortality.
- M-08** Define the needs of caregivers and persons with dementia, including Alzheimer’s disease and younger onset, as they relate to employment and employers.
- M-09** Conduct a national-level literature review to identify public health interventions that are effective in

decreasing preventable hospitalizations among persons with dementia, including Alzheimer’s disease, and disseminate findings.

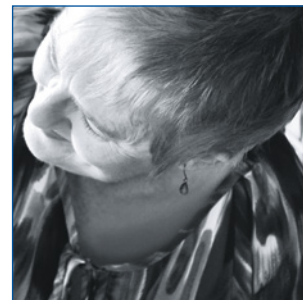
- M-10** Conduct a national-level review of caregiver programs and policies consistent with *The Guide to Community Preventive Services* methodologies.
- M-11** Examine the Chronic Disease Self-Management Program and other evidence-based programs to determine their ability to include persons with dementia and their care partners.
- M-12** Update and disseminate national-level reviews on the public health impact of physical activity programs and other behavioral risk factors associated with cognitive health and impairment.
- M-13** Conduct a national-level literature review on the potential and optimal use of technology for delivering best practices in programs for caregivers and persons with dementia, including Alzheimer’s disease.

Examining Co-Occurring Chronic Conditions

Investigators at the University of Washington received funding from CDC's Healthy Aging Program for a 3-year project (2011–2013): *Examining the Impact of Cognitive Impairment on Co-occurring Chronic Conditions and Geriatric Syndromes*. This project is being conducted in partnership with members of the CDC's Healthy Aging Research Network, a thematic network of the Prevention Research Centers that is funded by the Healthy Aging Program. The study was designed to examine the effects of multiple chronic conditions (dementia plus other chronic illnesses or geriatric syndromes) on various health outcomes such as functioning, depression, and mortality. The resulting findings from the literature review may assist public health practitioners and researchers in developing messages about the effect of cognitive impairment on public health strategies and policies as well as identifying gaps in research. Understanding the effect of depression and dementia can also help inform the design and delivery of evidence-based care-management programs for depression. A complementary effort will be an inventory of databases that include dementia and other chronic conditions, with the hope that this inventory will promote efforts to fill research gaps identified through the literature review.

This project is an example of efforts to implement the **Department of Health and Human Services' Strategic Framework on Multiple Chronic Conditions**, an innovative private-public sector collaboration to coordinate responses to a growing public health challenge. The strategic framework is designed to reduce the risks of complications and improve the overall health status of individuals with multiple chronic conditions by fostering change within the system; provide more information and better tools to help healthcare professionals as well as consumers learn how to better coordinate and manage care; and facilitate research to improve oversight and care.

Action Items



Educate and Empower the Nation

Public health plays an important role in informing the nation about the causes of disease, injury, and disability; ways to prevent and treat them; and strategies to preserve overall quality of life. This role is critical for both physical and cognitive health issues, particularly in light of the heightened fear surrounding dementia and the uncertainties about prevention. It is important to raise public awareness and improve access to available information and resources.

- E-01 Identify and promote culturally appropriate strategies designed to increase public awareness about dementia, including Alzheimer’s disease, to reduce conflicting messages, decrease stigma, and promote early diagnosis.**
- E-02 Create awareness by contributing public health information and data about cognitive health and impairment to national reports and partners.**
- E-03 Encourage public health entities to provide links on their Web sites to local, state, and national dementia resources, including those specific to Alzheimer’s disease and caregiving, such as www.alzheimers.gov.**

Using the Behavioral Risk Factor Surveillance System (BRFSS) to Understand Caregiving Prevalence and Association with Health Factors

With the support from CDC and state BRFSS Coordinators, a BRFSS **Caregiver module** is available. Each state can ask a common set of questions about caregiving and align those questions with “core” questions to examine a variety of issues such as health status and emotional and social support. Five states included the Caregiver Module on the 2010 BRFSS. They learned, for example, that caregivers of persons with Alzheimer’s disease or dementia provided care over a longer period of time and were more likely to report that caregiving created or aggravated their own health problem compared to other caregivers (Bouldin & Andresen, 2010). This reinforces the need for strategies aimed at caregivers of persons living with Alzheimer’s disease. Using this module along with the Cognitive Impairment module could provide valuable insights to states.

References

Bouldin ED, Andresen E. *Caregiving across the US. Caregivers of persons with Alzheimer’s disease or dementia in Connecticut, New Hampshire, New Jersey, New York, and Tennessee.* Alzheimer’s Association. 2010. www.alz.org/publichealth.

Expanding Information About the Public’s Beliefs and Concerns About Cognitive Health and Impairment

Developing measures to assess and track changes in attitudes of consumers and healthcare providers can help inform communication messages related to cognitive health and appropriate dissemination methods for future health promotion campaigns. Working with a set of partners, CDC and the Healthy Aging Research Network are examining consumers’ and healthcare providers’ attitudes and beliefs about cognitive health and dementia using available data sources. Two surveys, HealthStyles and DocStyles, which are proprietary databases of Porter Novelli and licensed by the CDC for **analysis in health communication planning**, have been modified to include a set of questions about beliefs and practices related to cognitive health as well as dementia and caregiving. This **information** will be important for understanding perceptions today as well as over time.

Action Items



Helping the public take recommended actions to promote cognitive health requires clear and consistent messages about what is known—and what is yet to be discovered. Robust and reliable coordination of prevention and risk reduction messages will minimize confusion and ensure that public, private, and non-profit organizations serve their respective constituencies effectively and reliably.

- E-04** Coordinate national and state efforts to disseminate evidence-based messages about risk reduction for preserving cognitive health.
- E-05** Promote consistency of cognitive health messages among national, state, and local levels using models such as the National Diabetes Education Program.
- E-06** Identify and promote strategies for the public about how to communicate effectively and sensitively with persons with dementia, including Alzheimer’s disease, and their families.

“We can no longer overlook the fear and concern shared by aging Americans and their adult children. Additional work is needed to ensure that the nation is informed about cognition and its impact on families and communities, and updated over time as scientific discoveries emerge.”

Marilyn Albert, PhD
Johns Hopkins Alzheimer’s Disease Research Center



The strengths and capacities of public health can be particularly valuable in advancing communication in four specific areas: advance care planning, clinical trials and studies, younger-onset dementia, and abuse and exploitation. Public health can raise awareness and sensitivity about these issues, and work with aging services networks, healthcare provider networks, and other partners at state and local levels.

E-07 Promote advance care planning and advance financial planning to care partners, families, and individuals with dementia in the early stages before function declines.

E-08 Promote appropriate partnerships and strategies to educate and increase local participation in clinical trials and studies on cognitive health and impairment.

E-09 Develop strategies to promote the availability of services for people with younger-onset dementia, including Alzheimer’s disease.

E-10 Promote awareness of abuse and exploitation and support related prevention efforts as they relate to persons with dementia, including Alzheimer’s disease.

“Creating a new road map for cognitive health provides a new window of opportunity to promote health equity.”

J. Neil Henderson, PhD
University of Oklahoma

Special Challenges of Younger Onset Alzheimer's Disease

Although risk for developing Alzheimer's disease increases with age, it has been estimated that between 220,000 and 640,000 people under age 65 in the U.S. have Alzheimer's or other dementias, defined as **younger onset**. These individuals and their care partners face several unique challenges. Diagnosis of younger onset often is delayed by several months or years because symptoms are attributed to other external factors or inaccurate diagnoses. Individuals with younger onset are often raising their families—and some also are caring for elderly parents. Workplaces can become stressful environments because colleagues or employers may not understand changes in behavior or work performance. Individuals who leave the workplace before receiving a diagnosis could be denied assistance that would otherwise be provided to individuals with disabilities, and also may lose health insurance coverage provided through their employers. Additionally, individuals with younger onset face the loss of income in the prime earning years and may not be eligible for certain support or financial services because they do not meet the age eligibility requirements or they may not be aware that they could qualify for disability benefits.

Alzheimer's disease occurs three to five times more often among people with **Down syndrome** than the general population, and often occurs at a younger age than for other adults.

A special task force has been created by the U.S. Department of Health and Human Services to improve care for special populations, including individuals with Down syndrome and those with younger onset.

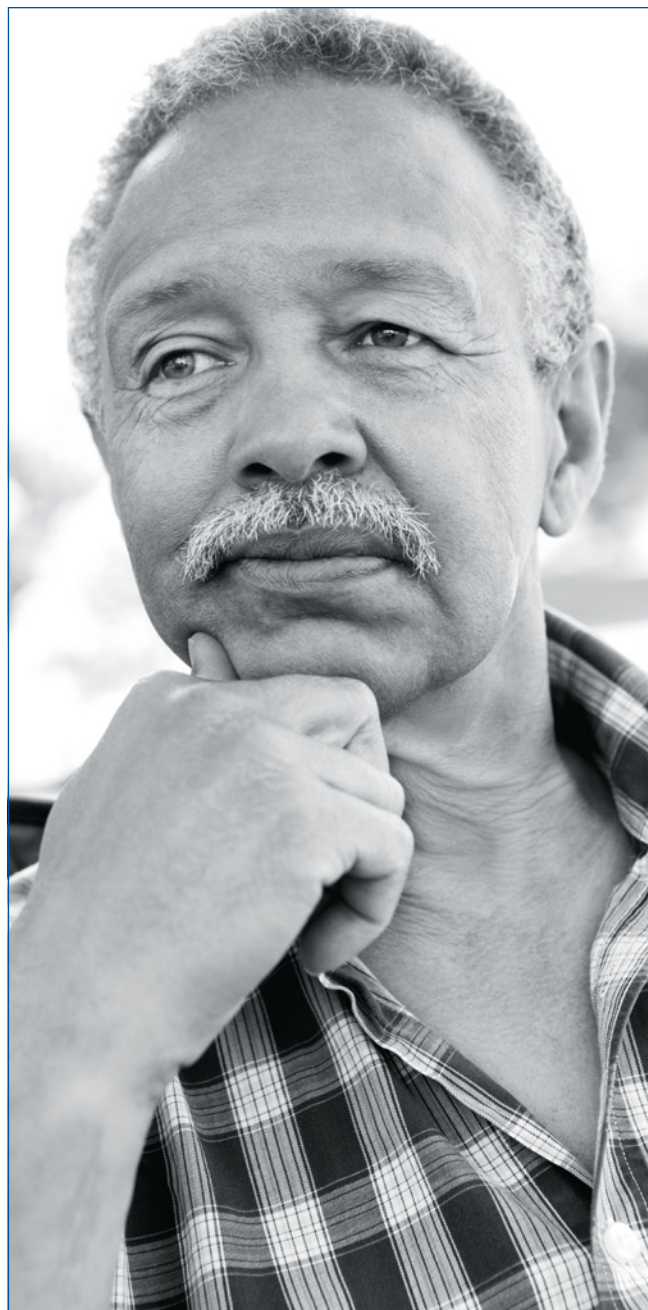
Additionally, people with younger-onset dementia are speaking out about their unique needs and forming support networks. In 2006, for example, the **Alzheimer's Association National Early-Stage Advisory Group** was formed. It includes individuals from across the U.S., including those with younger-onset Alzheimer's, who provide their unique insights on the needs of people living with Alzheimer's and their caregivers. In 2012, the Early-Stage Advisors developed tips about how to combat stigma based on their personal experiences, which was published during **World Alzheimer's Month**. States can help by offering programs and services for people with Alzheimer's disease, regardless of their age.

Importance of Clinical Trials and Recruitment of Diverse Volunteers

Thanks to advances in understanding dementia, including Alzheimer's disease, scientists are making progress toward identifying ways to help diagnose, slow, treat, and ultimately prevent the disease. As basic research advances, continued progress will depend, in large part,

on volunteers willing to participate in **clinical trials and studies**.

To find out whether a drug, intervention, or diagnostic tool is safe and effective, it needs rigorous testing. In the U.S., at any given time there are more than **150 clinical trials** related to Alzheimer's disease and cognitive decline needing at least 50,000 participating volunteers. To reach that goal, researchers will need to screen at least **half a million potential participants** in communities across the U.S. Since interventions may work differently for some groups than others, it is important to recruit diverse volunteers—encompassing a range of ages and backgrounds—to fully test the safety and effectiveness of interventions. For that reason, clinical trials and studies seek to recruit individuals of diverse backgrounds and cognitive function. This requires creative recruitment strategies that fully inform eligible participants about the **risks and benefits of the study**, secure participation, ensure that participant questions are answered along the way, and, in the end, report overall study results to volunteers.



Action Items



Develop Policy and Mobilize Partnerships

The Healthy Brain Initiative is committed to integrating cognitive health into the broad spectrum of public health work and focuses on increasing quality of life for those with cognitive decline. To the extent possible, cognitive health needs to be included as a major consideration in strategic planning for other public health efforts, chronic diseases and issues related to aging and caregiving. In addition, dedicated state plans for Alzheimer’s disease and other dementias can be considered as part of that larger picture.

P-01 Collaborate in the development, implementation, and maintenance of state Alzheimer’s disease plans.

P-02 Integrate cognitive health and impairment into state and local government plans (e.g., aging, coordinated chronic disease, preparedness, falls, and transportation plans).

P-03 Promote incorporation of cognitive health and impairment into state and local public health burden reports.

“As we worked on the Road Map, Superstorm Sandy occurred—reminding us that public health must continue to identify and prepare to meet the needs of all vulnerable populations before the next crisis, including people with cognitive impairment and their caregivers.”

David Hoffman, MEd, CCE
*Board Member, National Association
of Chronic Disease Directors*

State Alzheimer's Disease Plans

Alzheimer's disease plans aim to create the infrastructure and accountability to create programs and policies regarding the needs of people with the disease and supporting structures in communities. This is referred to as being **"dementia-capable"**—being skilled in identifying people with dementia and working effectively with them and their caregivers, knowledgeable about the kinds of services needed, and aware of agencies and individuals that provide such services. A comprehensive plan helps to unite state public health partners around a range of issues including: creating dementia-capable support services for people at all stages of the disease; reporting state estimates of Alzheimer's disease prevalence; assuring quality of long-term care; providing home and community services; helping identify and track the availability of diagnostic services; protecting the safety of persons who wander; and supporting caregivers and healthcare professionals. As of April 2013, 28 states have published **Alzheimer's disease plans**.

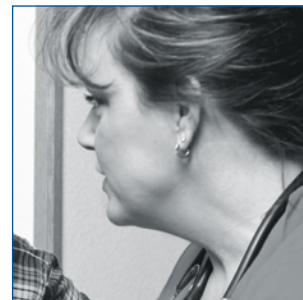
Nearly all of the published plans include public health recommendations and strategies for monitoring the burden of cognitive decline, public awareness, early detection, and communication about brain health.

A majority of state plans include early detection and diagnosis as a main focal point, and several states have taken significant steps toward accomplishing established goals in such areas as creating public awareness campaigns and promoting access to early detection and diagnosis.

Considering Dementia in Preparedness Planning

Because dementia affects cognitive ability and judgment, those with cognitive impairment may be particularly vulnerable during all-hazard emergencies, yet their special needs may not be recognized during emergency planning and preparedness activities. Of the confirmed fatalities in Hurricane Katrina, it is unknown how many people had dementia, but approximately 64% were older than age 60. During **Hurricane Sandy** several older adults drowned alone in their homes. To help prevent future devastating situations like these, it is important to **include experts** in cognitive impairment, individuals with cognitive impairment and their care partners in local and state **preparedness planning efforts**, and to train responders and shelter staff about signs and symptoms of dementia, or conditions that can mimic cognitive impairment. Just as with the general population, it is important for individuals with dementia and their care partners to have a personal **preparedness plan** so that they can deal with disasters of all sorts much more effectively when they occur.

Action Items



Efforts at the national level to integrate cognitive health into ongoing planning and policy initiatives offer opportunities to engage additional national and state partners. Adopted national health objectives can be leveraged by states, and synergies can be gained by examining potential policies in a concerted fashion.

- P-04** Integrate Healthy People 2020 objectives on “Older Adults” and “Dementias, including Alzheimer’s disease” topic areas into state-based plans.
- P-05** Engage national and state organizations and agencies to examine policies that may differentially impact persons with dementia, including Alzheimer’s disease.

“We must capitalize on state efforts to coordinate public health chronic disease programs and include cognitive health in that larger picture.”

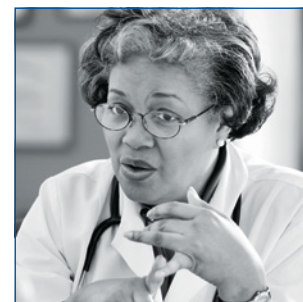
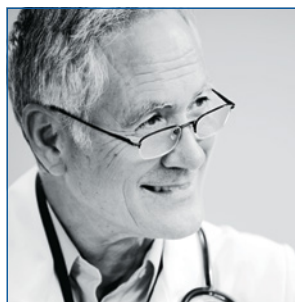
Sharon Moffatt, RN, BSN, MSN
Association of State and Territorial Health Officials

Integrating Early Detection and Diagnosis into Medical Homes

ACT on Alzheimer's is a voluntary, statewide collaboration focused on transforming Minnesota's medical and long-term care systems and communities to better support individuals with Alzheimer's disease and other dementias and their families. Its members—representing over 50 medical, academic, community, government, business, and non-profit organizations throughout the state—are guided by a common vision, five goals, and specific **success measures** by which to gauge progress. The first of those goals is “increase early identification of Alzheimer's disease and improve ongoing treatment based on recommended care practices.” Corresponding success measures call for incorporating dementia specific practices into applicable providers' curricula; and offering a practice algorithm that supports screening, early diagnosis and intervention, and quality care. The effort embraces the innovative, cost-saving **medical care home model** for delivering preventive and primary care, which focuses on patient needs, improved access to care, and increased care coordination. If successful, by June 2018, 75% of medical care home providers who received the practice algorithm will have implemented that algorithm into their practices.



Action Items



Assure a Competent Workforce

As cognitive health continues to gain recognition as an important public health issue, state and local public health professionals will be called upon to translate current and emerging research into practice. Competency-based educational strategies and materials are needed to give the public health workforce the knowledge and skills for carrying out this vital role.

W-01 Develop strategies to help ensure that state public health departments have expertise in cognitive health and impairment related to research and best practices.

W-02 Develop introductory, basic materials for public health professionals on cognitive health and impairment to help them understand their role.

“People with Alzheimer’s disease and other dementias can be found throughout the healthcare system, even if they are not recognized as such. Community-clinical partnerships are essential to address this burgeoning crisis.”

Elizabeth Edgerly, PhD
*Alzheimer’s Association
of Northern California/Northern Nevada*



The Impact of Care Consultations

The **North Dakota Dementia Care Services Project** (DCSP) began in January 2010, with funding from the North Dakota Department of Human Services, Aging Services Division, to the Alzheimer's Association of Minnesota/North Dakota. Newly hired care consultants meet with people with dementia and their caregivers to increase knowledge and decrease caregiver stress by assessing needs; identifying issues, concerns, and resources; developing care plans and referrals; and providing education and follow-up. Employed by the Alzheimer's Association, care consultants have a background in counseling, social work, or long-term care administration; all have a bachelor's degree and many a relevant master's degree. They are supervised by a clinical services director with a master's in social work and extensive experience in care consultation.

The impact of these consultations was immediate and significant. An evaluation by the Center for Rural Health at The University of North Dakota School of Medicine and Health Sciences documented—

- After just 3 months: A savings of \$60,064 due to decreased hospital stays, 911 calls, and ambulance services.
- After 6 months: A healthcare savings of \$323,098 and a doubling of the percent of caregivers who completed important dementia care-related tasks: establishing power of attorney, instituting healthcare directives and acquiring long-term care insurance for their person with dementia.
- After 9 months: an **estimated healthcare savings** of \$1,838,519 due to delays in placing persons with dementia in long-term care facilities.

Action Items



Educational initiatives that maximize partnerships between academic institutions and practice and care partner organizations, and align with major competency-based efforts, can increase awareness, knowledge, and abilities of healthcare providers who interact with and support people with cognitive impairment and their care partners. By defining various providers' roles, offering formative and continuing education, preparing professionals, and providing practical tools and resources, strong partnerships can be forged in states and communities to enhance community-clinical capacity for effective detection, early diagnosis, referral, and care.

W-03 Support continuing education efforts that improve healthcare providers' ability to recognize early signs of dementia, including Alzheimer's disease, and to offer counseling to individuals and their care partners.

W-04 Identify appropriate roles and determine effectiveness of community health workers, promotoras, patient navigators, and paraprofessionals with respect to care related to dementia, including Alzheimer's disease.

W-05 Develop strategies to help ensure that healthcare professionals recognize the role of care partners in the care coordination of persons with dementia, including Alzheimer's disease.

W-06 Educate healthcare providers about validated cognitive assessment tools that could be administered in such settings as physicians' offices, clinics, emergency rooms, and acute care hospitals' admission offices.

W-07 Increase awareness among healthcare professionals about care partner health.

Promoting Detection and Diagnosis

As many as half of those who meet the diagnostic criteria for dementia have not received that diagnosis from a physician (Boustani, Peterson, Hanson, Harris & Lohr, 2003; Bradford, Kunik, Schulz, Williams & Singh, 2009). **Early detection and diagnosis** are essential to providing the best medical care and outcomes for those at any stage of the disease. Even without a way to cure or slow the progression of dementia, including Alzheimer's disease, an early formal diagnosis offers the best opportunities for intervention and better outcomes. With a diagnosis in hand, individuals and their caregivers can access available treatments, build a care team, and better manage co-existing chronic conditions. Additionally, early **diagnosis** allows for some forms of cognitive impairment, such as those caused by drug interaction and dosage or a vitamin B12 deficiency, to be reversed. A meta-analysis of 39 published articles showed that 9% of individuals experiencing dementia-like symptoms had potentially reversible forms of cognitive impairment upon proper workup (Clarfield, 2003).

References

Boustani M, Peterson B, Hanson L, Harris R, Lohr KN. *Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force*. *Annals of Internal Medicine* 2003;138(11):927–37.

Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. *Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors*. *Alzheimer Disease & Associated Disorders* 2009;23(4):306–14.

Clarfield AM. *The decreasing prevalence of reversible dementias: an updated meta-analysis*. *Archives of Internal Medicine* 2003; 163(18):2219–29.

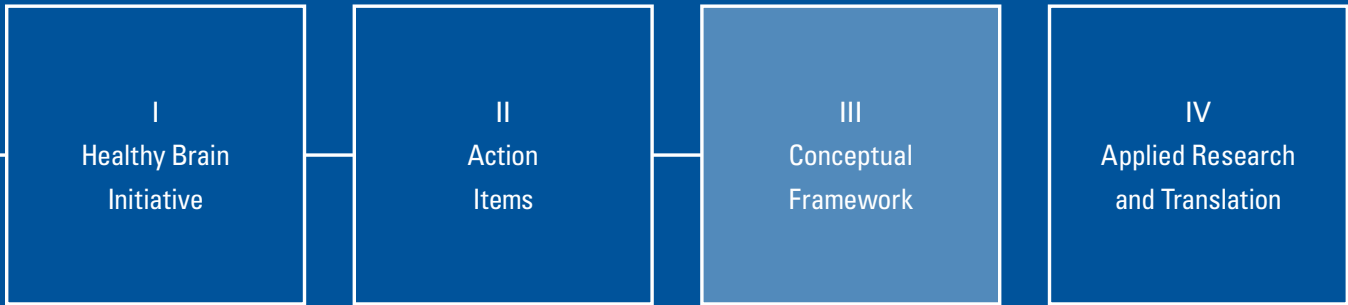
Non-Pharmacological and Care Practice Interventions

A **recent white paper** (Administration on Aging & Alliance for Aging Research, 2012) identifies 44 effective interventions to support people with Alzheimer's disease and their caregivers at home and in the community. Based on the proceedings of a meeting in 2012 and a review of the literature, these interventions had been studied using randomized controlled trials and had documented positive effects on a broad set of outcomes. The report details such key features as: who received the intervention, what type and stage of condition, where the intervention was delivered, and through what delivery mechanism. Additionally, the report describes the current state of **translational studies**, research gaps, support to move more **effective interventions** into practice, and need for strategies and tools to promote the alignment of specific interventions with persons and families in need. Despite the increasing numbers of effective interventions, they are not well known to the practice community and warrant further attention.

References

Administration on Aging and Alliance for Aging Research. *White paper: translating innovation to impact: evidence-based interventions to support people with Alzheimer's disease and their caregivers at home and in their communities*. September, 2012. www.agingresearch.org/section/translating_innovation_to_impact.a





Conceptual Framework

Public Health Core Functions

Public health efforts have yielded remarkable achievements during the last century and continue to make significant progress (CDC, 1999). In 2010, CDC published the 10 top public health achievements of the first decade of the 21st century (CDC, 2011b): reducing heart disease and death, better cancer prevention, doing a better job of fighting use of tobacco, improvements in preparedness, declines in vaccine-preventable diseases, better maternal and infant health, improved occupational safety, fewer childhood lead poisonings, greater

control over infectious diseases like tuberculosis, and improving motor vehicle safety. The report further underscores the importance of fundamental public health tools such as the establishment of surveillance systems, implementation of research findings, and development of effective public health programs. These tools enable public health to carry out the three core functions of public health recommended by the Institute of Medicine in *The Future of Public Health* (1988): assessment, policy development, and assurance.

Conceptual Framework



Assessment refers to the systematic collection and analysis of data including information on health status, health needs, and other public health and health issues (IOM, 1988). The assessment function also includes diagnosing and investigating health hazards in the community.

Policy development includes informing, educating, and empowering the public on health issues of concern; promoting awareness of public health services; and promoting health education initiatives that contribute to individual or collective changes in health knowledge, attitudes, and practices that make for a healthier community. It also includes promoting partnerships and actions designed to identify and solve health issues, as well as creating policies and planning activities to support various health efforts.

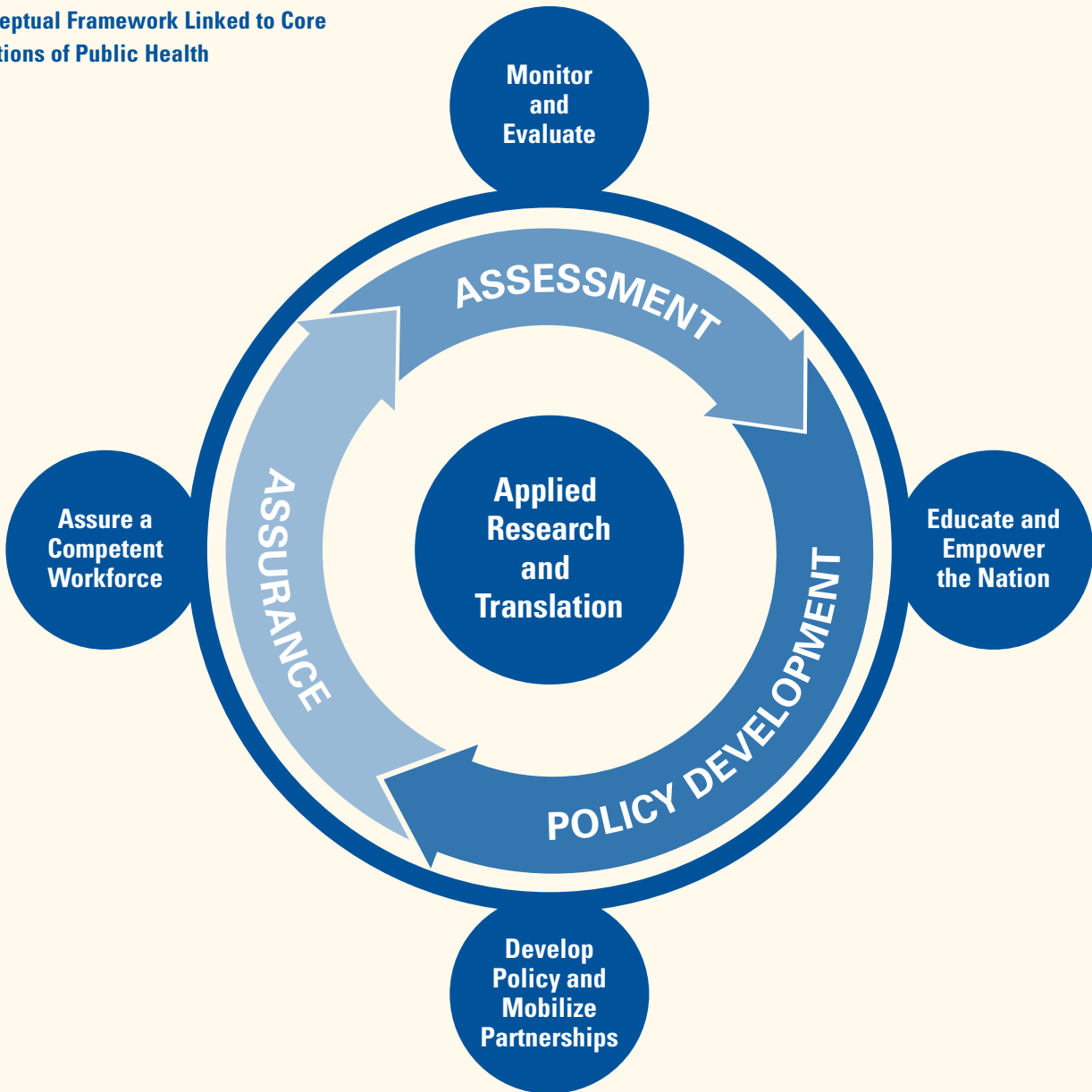
Assurance activities provide a guarantee that the services needed to achieve agreed-upon goals are provided. This third core public health function includes a wide range of activities involving managing resources and developing organizational structures; implementing programs for priority health needs; and evaluating and providing quality assurance to ensure that

programs are consistent with plans and policies—or that needed corrective actions are taken promptly.

Assuring the delivery of public health services requires a public health infrastructure at federal, tribal, state, and local levels that possesses: a qualified and capable workforce; functional, up-to-date data and information systems; and the capacity to assess and respond to public health needs (USDHHS, 1997). Increasing attention to public health infrastructure has underscored the importance of systems research in identifying and promoting the evidence base for community interventions, with a critical focus on applied research and translation. The results of systems research help determine the need for the effective organization, administration, and financing of public health services (USDHHS, 1997).

The application of these public health core functions to cognitive health offers hope of similar achievements as scientific knowledge advances. The Healthy Brain Initiative Road Map conceptual framework integrates the public health core functions plus systems research with the four domains identified through concept mapping.

Conceptual Framework Linked to Core Functions of Public Health



Conceptual Framework



Guiding Principles

The Healthy Brain Initiative is grounded in a firm commitment to collaborative public-private partnerships as a prerequisite for achieving meaningful outcomes. As such, the Leadership Committee of the Road Map wishes to build upon the National Plan to Address Alzheimer's Disease and other relevant plans and strategic frameworks. The Committee recognizes the vital contributions of private, non-profit, and governmental partners at the national, state, and local levels to address and promote cognitive functioning and the needs of care partners, and embraces areas where synergistic opportunities exist. Several key principles underlie the collaborative approach to addressing and promoting cognitive functioning and attending to the needs of care partners:

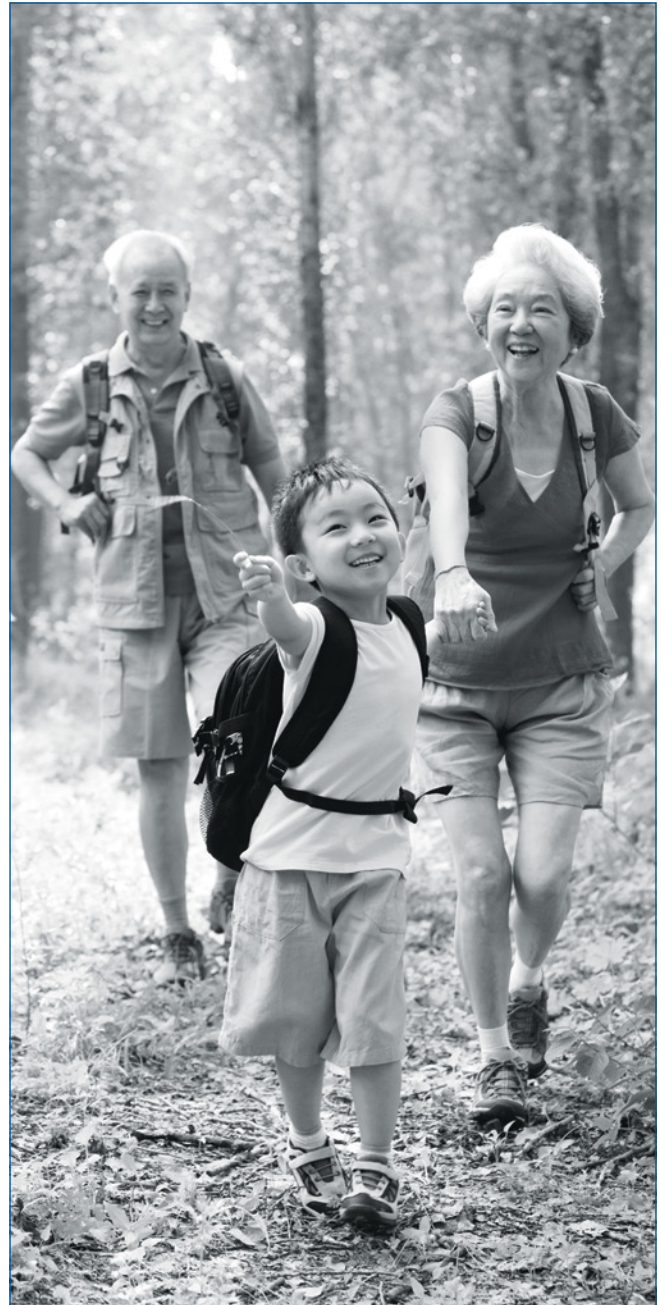
Address cognitive functioning along a continuum. Cognitive health can be viewed along a continuum—from the promotion of optimal functioning to early diagnosis of mild cognitive impairment to support services for severe dementia or Alzheimer's disease. Tasks involved with cognitive function

include: language, thought, memory, executive function (the ability to plan and carry out tasks), judgment, attention, perception, remembered skills such as driving, and the ability to live a purposeful life.

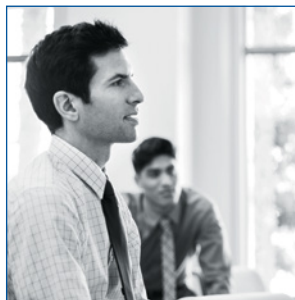
Commit to promoting health equity. Health equity is defined as the “attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities” (USDHHS, 2010). As documented in the *2011 Department of Health and Human Services' Action Plan to Reduce Racial and Ethnic Health Disparities, A Nation Free of Disparities in Health and Health Care*, the leading health indicators have demonstrated little improvement in disparities over the past decade according to analyses of progress on key objectives in Healthy People 2010 (USDHHS, 2011). The recently issued Healthy People 2020 objectives look beyond disparities toward greater health equity.

The Leadership Committee embraces health equity and recognizes its value in shaping policy initiatives, communication strategies, lifestyle interventions, and population-based surveillance related to cognitive health and impairment.

Stay grounded in science. Through public health surveillance, epidemiology, and applied research, public health can contribute to the understanding of cognitive functioning and, with biomedical and clinical research, identify promising interventions that may be effective in promoting or protecting it. The Leadership Committee recognizes that this process is evolutionary, requiring methods and processes to build upon what is currently known, share new discoveries as they emerge, and support advancements through promoting involvement in clinical studies and applied research.



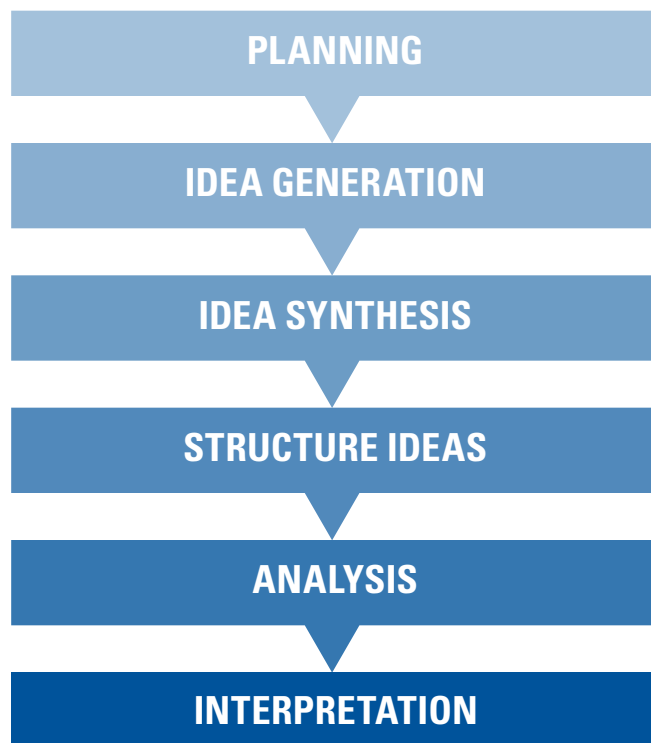
Conceptual Framework



Use of Concept Mapping to Identify Action Items

The Leadership Committee, made up of 15 experts from state and national organizations, provided overall guidance and coordination for the development and dissemination of the Road Map (Appendix A). The final product reflects the culmination of a process that merged critical input from the Leadership Committee with the voices of more than 280 informed and knowledgeable professionals in public health, aging, and Alzheimer’s disease who represented national, state, and local agencies, non-governmental organizations, and academic institutions.

A concept mapping process, which consists of a sequence of phases that yields a visual picture of a shared group consensus of ideas, was used to form a conceptual framework and identify action items for the Road Map. A concept map provides a pictorial representation of a set of ideas, which are clustered in groups so that a complex set of ideas can be more readily understood. The project was organized into three overarching phases following the six-step process of concept mapping.



The first phase included planning and idea generation. During this phase, the Leadership Committee agreed on the core question that needed to be addressed and developed this prompt: “A specific action that state or local public health could do—on their own or with other national, state, or local partners—to address or promote cognitive functioning for people living in the community and the needs of care partners is...”. Additionally, members of the committee reviewed background and introductory materials including the history of the effort and the definitions of terms and phrases such as cognition and care partners. They also identified individuals who would be invited to generate ideas related to the core question because of their experience and expertise about public health, research, and aging services as it relates to cognitive health and impairment.



Conceptual Framework



Between September 11, 2012 and September 30, 2012, 287 participants were invited to contribute ideas in response to the core question using a secure Web site (The Concept System® Global MAX™, 2012) or by mailing or faxing their ideas. The ideas were provided anonymously to encourage participation and help avoid any potential inhibition or bias in submitted responses. As a consequence, response rates or the average number of items submitted per respondent are unknown. However, there were 151 unique visits to the Web site and a total of 370 ideas were generated.

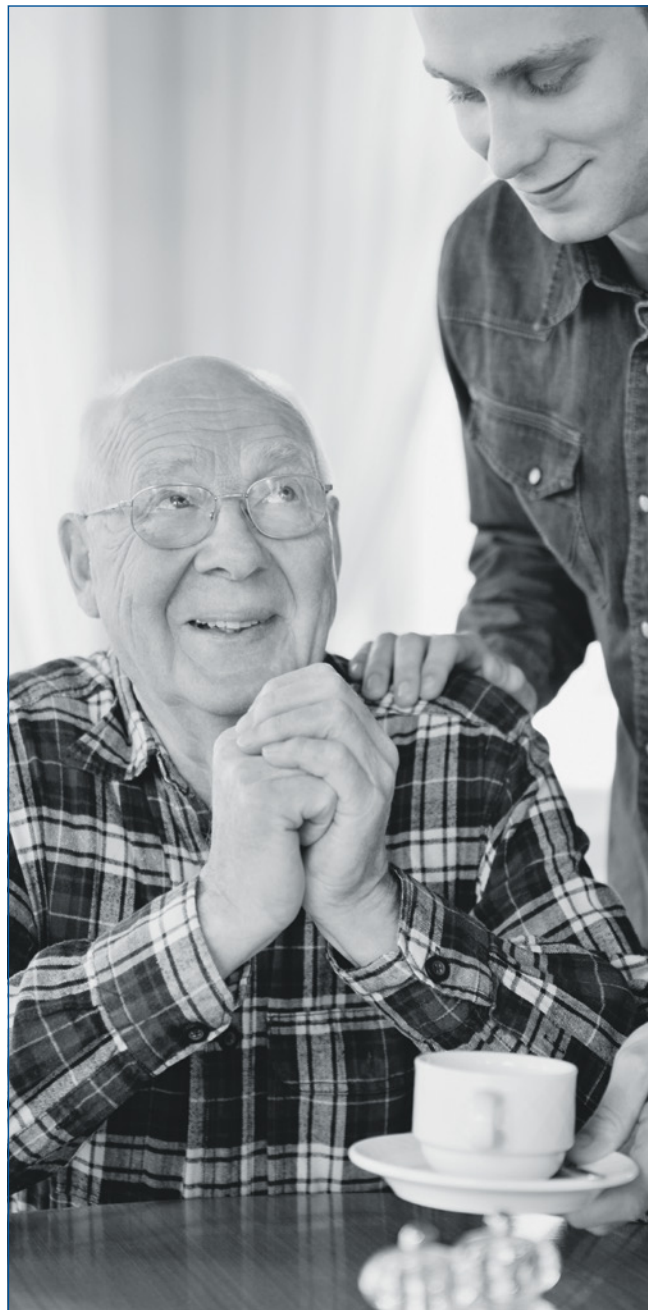
Members of a planning group (Appendix A) reviewed the statements that had been generated and eliminated repetitive statements and those not addressing the focus question. The remaining 80 ideas were presented to the Leadership Committee for further scrutiny.

A total of 54 unique statements were identified using the following criteria:

- **Is credible based on solid science or best practices;**
- **Reflects an appropriate role for state and local public health agencies on their own or with their national, state, and local partners;**
- **Addresses a single action; and**
- **Is sufficiently broad to encompass many activities that could be undertaken by states and partners depending on needs and resources.**

The second phase focused on idea synthesis and structuring through the generation of concept maps and rating of ideas for criticality and feasibility. Members of the Leadership Committee and an additional 64 individuals were invited to sort the ideas into themes; the Leadership Committee and an additional 274 individuals were invited to rate the 54 ideas. This phase was conducted between October 31, 2012 and November 30, 2012.

For sorting, individuals were asked to group the statements into categories, or themes, based on similarity of ideas. Participants used the project's Web site for this sorting and were asked to create their own categories. They were told that each statement could be placed into only one category, and that the sorting process should result in more than one category but fewer categories than the total number of statements.



Conceptual Framework



For rating, each idea was considered on two dimensions:

Criticality – How critical each idea is for state or local public health to pursue in the next 5 years, on their own or with support from national, state, or local partners.

Feasibility – How feasible each idea is for state or local public health to pursue in the next 5 years, on their own or with support from national, state, or local partners.

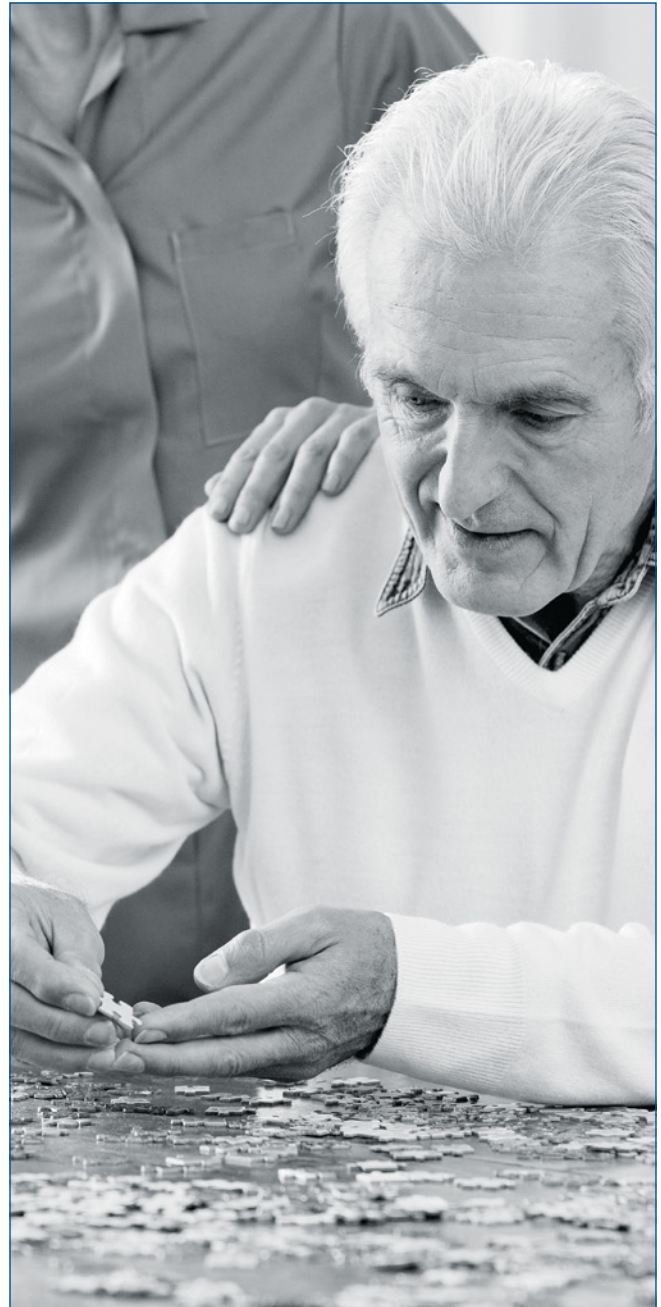
Again, because participation was anonymous, exact response rates could not be calculated. However, based on unique identifiers, an estimated 53% of those invited to sort completed the task and about one-third of those invited rated the items. These completion rates are comparable to other concept mapping projects (Anderson et al., 2006; Rosas & Kane, 2012).

The third phase included analysis and interpretation of maps. A concept mapping firm conducted a systematic and sequential analysis following established methods for group concept mapping (Trochim, 1989; Kane & Trochim, 2007). The analysis of the sorting data produced a network of ideas that represented the relationship between those ideas, as organized by the participants. The ideas were then grouped together, based on their similarity, to represent larger concepts.

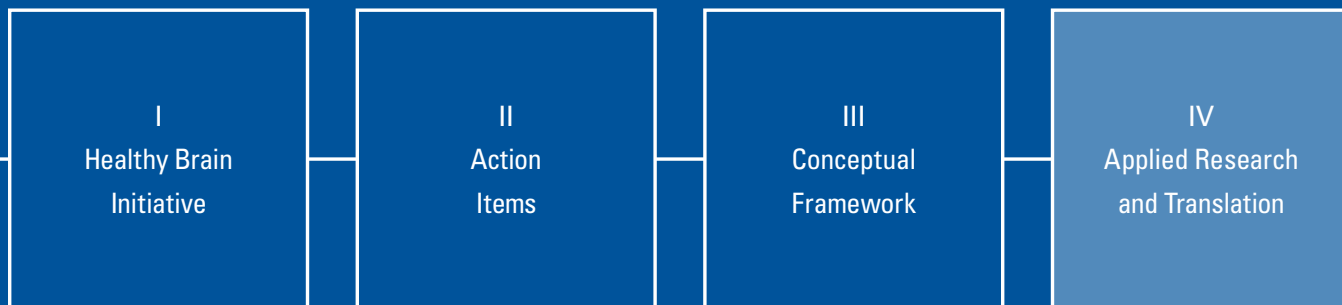
As a result of the analysis and input from the Leadership Committee, the ideas were grouped into four clusters and labeled in alignment with the Essential Services of Public Health (USDHHS, 1997) as follows:

- Monitor and Evaluate
- Educate and Empower the Nation
- Develop Policy and Mobilize Partnerships
- Assure a Competent Workforce

The final concept map serves as the framework for the Road Map. Additionally, using the analyzed rating data as well as the set of criteria outlined above, the Leadership Committee examined and provided input on a subset of action items to be considered for inclusion in the Road Map. The 35 final action items are provided in Section II along with rationale.







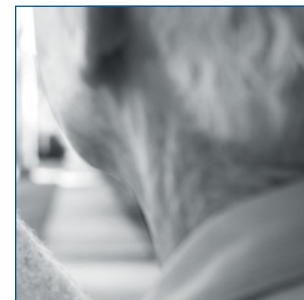
Applied Research and Translation

The collective undertaking of state and national partnerships to maintain or improve the cognitive performance of all adults is only as effective as the evidence on which it is based. During the five-year time span of this Road Map, current and future research will yield new knowledge to better understand the public health burden of cognitive impairment, refine current practices and interventions to promote cognitive functioning, and help support the complex needs of individuals living with cognitive impairment and their care partners.

A few notable areas on the horizon—

Prevention research: An increasing research focus is anticipated on the vast majority of Americans living without cognitive impairment who “still face the looming specter of dementia in much later life and very likely have experienced subtle declines in cognitive function” (Wagster et al., 2012). Among the key research questions is what impact physical activity and other behavioral interventions have on maintaining healthy brains and preventing cognitive decline.

Applied Research and Translation



Expanded use of technology: Few fields continue to evolve as rapidly as technology. Tools that were hard to imagine only a few years ago are now essential for everyday functioning. Some have great potential for improving the quality of life of individuals with cognitive impairment and their care partners. Audible and visual prompts, for example, in Geographic Information Systems and Global Positioning Systems, can make it easier for them to navigate their communities safely and gain greater mobility and independence.

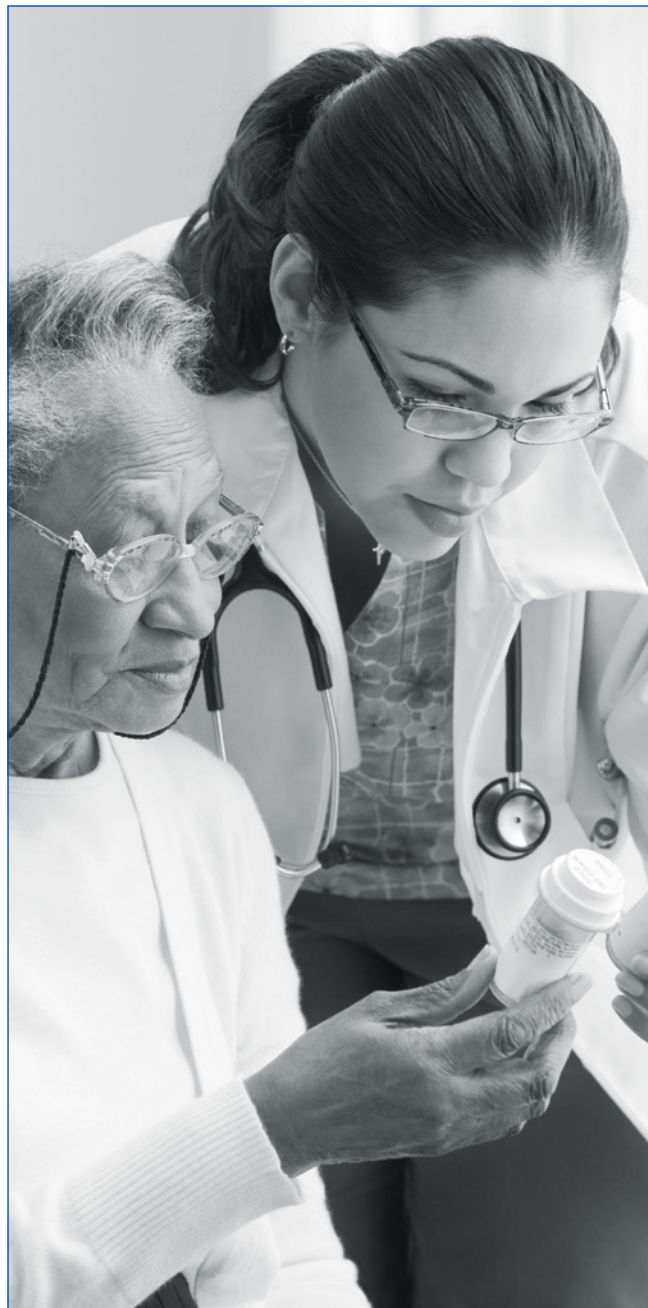
Focus on promoting mobility: Communities are increasingly cognizant of the value of optimal mobility, defined as “the ability to safely and reliably go where you want to go, when you want to go, and how you want to get there (Satariano et al., 2012).” The concept broadly includes basic ambulation, transferring from a bed to a chair, walking for leisure and the completion of daily tasks, engaging in activities associated with work and play, exercising, driving a car, and using various forms of public transport. This ability is important for all community-dwelling older adults through the life course, including individuals with cognitive impairment and their care partners.

“Unless public health engages our partners to act quickly and strategically, issues of aging—falls, mobility, cognitive health—will consume our healthcare system.”

Toni Miles, MD, PhD
Institute of Gerontology, University of Georgia

Community-clinical linkages: In recent years, the public health community has focused on developing stronger links between clinical and community providers for the delivery of a wide range of healthcare services (IOM, 2012). For cognitive impairment, these links could improve management of coexisting conditions; access to support groups and supportive services such as counseling, coordination of care, social services, and respite care; and sharing of information about available treatment options.

Rapid dissemination and implementation of research findings into widespread practice is crucial so that the benefits are equally available to all Americans, regardless of race/ethnicity, gender, socioeconomic, and geography. Accomplishing the actions in this Road Map will lay a solid foundation from which to anticipate and respond to emerging innovations and developments. By strengthening the capacity of public health agencies and leveraging strong state and national partnerships, energy and resources can be dedicated to incorporating cognitive health and impairment into ongoing chronic disease efforts at national, state, and community levels.





Appendix A: Committees and Contributors

Leadership Committee

Lynda Anderson, PhD (co-chair)
*Centers for Disease Control
and Prevention*

Robert Egge (co-chair)
Alzheimer's Association

Marilyn Albert, PhD
*Johns Hopkins Alzheimer's Disease
Research Center*

William Benson
Health Benefits ABCs

Vicky Cahan
*National Institute on Aging
at National Institutes of Health*

Alyssa Easton, PhD
Consumer

Elizabeth Ederly, PhD
*Alzheimer's Association of
Northern California/Northern Nevada*

Jill Myers Gadelmann, BS, RN
*Bureau Chief, Chronic Disease
Prevention and Management, Iowa
Department of Public Health*

Dona Goldman, RN, MPH
*Board Member, National Association
of Chronic Disease Directors*

J. Neil Henderson, PhD
University of Oklahoma

David P. Hoffman, MEd, CCE
*Board Member, National Association
of Chronic Disease Directors*

Toni Miles, MD, PhD
*Institute of Gerontology,
University of Georgia*

Sharon Moffatt, RN, BSN, MSN
*Association of State and
Territorial Health Officials*

Michael Splaine
Splaine Consulting

Jane Tilly, DrPH
*Administration on Community
Living/Administration on Aging*

Project Committee

CDC
Lynda Anderson, PhD

Angela Deokar, MPH

Carla Doan, MS

Alzheimer's Association
Matthew Baumgart

Robert Egge

Catherine Morrison, MPH

Consultants
William Benson
Health Benefits ABCs

Carol McPhillips-Tangum, MPH
*National Association of
Chronic Disease Directors*

Michael Splaine
Splaine Consulting

Writer/Editor
Susan Baker, MPH

Graphic Specialist
Colon Odette

Concept Systems, Inc.
Mary Kane, MS

Brenda K. Pepe, BA

Scott R. Rosas, PhD

Contributors

Dave Baldridge

Grant T. Baldwin, PhD, MPH

Elizabeth Smith-Boivin, MSHSA

Heather Bombei, LISW

David R. Brown, PhD

Anne Marie Caron, MSN, ANP-BC

Kimberly Clark, RN

Susan G. Cooley, PhD

Jeffrey L. Cummings, MD, ScD

Erin Drinnin, MSW

Cheryl Evans-Pryor, MA-G

Lynn Friss Feinberg, MSW

Di Findley

James E. Galvin, MD, MPH

Robyn L. Golden, MA, LCSW, ACSW

Kate Gordon, MSW

Joseph D. Hoyle, MD, MPH

Beth A. Kallmyer, MSW

Michele J. Karel, PhD

Brian Kaskie, PhD

Daniel Kaufer, MD

Michelle Kelman

Kate Krajci, AM, LCSW

Sue Lachenmayr, MPH, CHES

Richard W. Lindsay, MD

Katie Maslow, MSW

Mary Mittelman, DrPH

Jeneane Moody, MPH

Ellen Nau

Karen M. Pocinki, MA

Elizabeth Walker Romero, MS

Nina B. Silverberg, PhD

Carol L. Sipfle, BA, MPA

Philip D. Sloane, MD, MPH

Amy Slonim, PhD

Janet K. Specht PhD, RN, FAAN

Linda Teri, PhD

Laura Trejo, MSG, MPA

Peggy Vaughn, MGA

Jennifer L. Watson, MA

Amy Wiatr-Rodriguez, MSW

Jennifer L. Wood

Earl A. Zimmerman, MD

Appendix B: References

- Anderson LA, Day KL, Beard RL, Reed PS, Wu B. *The public's perceptions about cognitive health and Alzheimer's disease among the U.S. population: a national review*. *The Gerontologist* 2009;49(S1):S3-S11. doi: 10.1093/geront/gnp088.
- Anderson LA, Gwaltney MK, Sundra DL, Brownson RC, Kane M, Cross AW, et al. *Using concept mapping to develop a logic model for the Prevention Research Centers Program*. *Preventing Chronic Disease* 2006;3(1). www.cdc.gov/pcd/issues/2006/jan/05_0153.htm. Accessed March 6, 2013.
- Batsch NL, Mittelman MS. *World Alzheimer Report 2012: overcoming the stigma of dementia*. Alzheimer's Disease International, London, September, 2012. www.alz.co.uk/research/WorldAlzheimerReport2012.pdf. Accessed March 6, 2013.
- Blendon RJ, Benson JM, Wikler EM, Weldon KJ, Georges J, Baumgart M, Kallmyer BA. *The impact of experience with a family member with Alzheimer's Disease on views about the disease across five countries*. *International Journal of Alzheimer's Disease*, 2012, Article ID 903645, 9 pages, doi:10.1155/2012/903645.
- Boustani M, Peterson B, Hanson L, Harris R, Lohr KN. *Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force*. *Annals of Internal Medicine* 2003;138(11):927-37.
- Centers for Disease Control and Prevention. *Ten great public health achievements—United States, 1900-1999*. *MMWR Weekly* 1999;48(12):241-3.
- Centers for Disease Control and Prevention. *Behavioral Risk Factor Surveillance System, BRFSS annual survey data, 2011a*. www.cdc.gov/brfss/questionnaires.htm. Accessed March 6, 2013.
- Centers for Disease Control and Prevention. *Ten great public health achievements—United States, 2001-2010*. *MMWR Weekly* 2011b;60(19):619-23.
- Centers for Disease Control and Prevention. *The CDC Healthy Brain Initiative: progress 2006-2011*. Atlanta, GA: CDC; 2011c. www.cdc.gov/aging/pdf/HBIBook_508.pdf. Accessed April 22, 2013.
- Centers for Disease Control and Prevention. *Self-reported increased confusion or memory loss and associated functional difficulties among adults aged ≥60 years—21 states, 2011*. *MMWR Weekly* 2013; 62(18): 345-50. www.cdc.gov/mmwr/pdf/wk/mm6218.pdf.
- Centers for Disease Control and Prevention and the Alzheimer's Association. *The Healthy Brain Initiative: a national public health road map to maintaining cognitive health*. Chicago, IL: Alzheimer's Association; 2007. www.cdc.gov/aging/pdf/TheHealthyBrainInitiative.pdf. Accessed March 6, 2013.
- Corrigan P. *How stigma interferes with mental healthcare*. *American Psychologist* 2004;59:614-25.
- Elliott AE, Burgio LD, DeCoster J. *Enhancing caregiver health: findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention*. *Journal of the American Geriatrics Society* 2010;58:30-7.
- Family Caregiver Alliance. *Caregiver assessment: principles, guidelines, and strategies for change*. Report from a National Consensus Development Conference. Volume I. San Francisco, CA: Family Caregiver Alliance, 2006.
- Frank JC, Weiss J. *Public health workforce: preparing for an aging society*. In: Prohaska TR, Anderson LA, Binstock RH (eds). *Public Health for an Aging Society*. Baltimore, MD: Johns Hopkins University Press, 2012.
- Friedman DB, Rose, ID, Anderson LA, Hunter R, Bryant LL, Wu B, et al. *Beliefs and communication practices regarding cognitive functioning among consumers and primary care providers in the United States, 2009*. *Preventing Chronic Disease* (In press, April 2013).
- Grossberg GT, Christensen DD, Griffith PA, Kerwin DR, Hunt G, Hall EJ. *The art of sharing the diagnosis and management of Alzheimer's disease with patients and caregivers: recommendations of an expert consensus panel*. *Journal of Clinical Psychiatry (Primary Care Companion)* 2010;12(1),PCC.09cs00833.
- Hebert LE, Scherr PA, Beckett LA, Albert MS, Pilgrim DM, Chown MJ, et al. *Age-specific incidence of Alzheimer's Disease in a community population*. *Journal of the American Medical Association* 1995;273:1354-9.
- Hebert LE, Weuve J, Scherr PA, Evans, DL. *Alzheimer disease in the United States (2010-2050) estimated using the 2010 census*. *Neurology* 2003. www.neurology.org/content/early/2013/02/06/WNL.0b013e31828726f5 (Published Ahead of Print on March 6, 2013 as 10.1212/WNL.0b013e31828726f5).
- Hurd MD, Martorell, P, Delavande, A, Mullen, KJ, Langa, KM. *Monetary costs of dementia in the United States*. *New England Journal of Medicine* 2013;368:1326-34. DOI: 10.1056/NEJMs1204629.
- Institute of Medicine. *The future of public health*. Washington (DC): National Academy Press, 1988. www.iom.edu/Reports/1988/The-Future-of-Public-Health.aspx.
- Institute of Medicine. *Retooling for an aging America: building the health care workforce*. Washington (DC): The National Academies Press, 2008. www.iom.edu/Reports/2008/Retooling-for-an-Aging-America-Building-the-Health-Care-Workforce.aspx.
- Institute of Medicine. *Primary care and public health: exploring integration to improve population health*. Washington (DC): The National Academies Press, March 2012. www.iom.edu/Reports/2012/Primary-Care-and-Public-Health.aspx.
- Kane M, Trochim WMK. *Concept mapping for planning and evaluation*. Thousand Oaks, CA: Sage Publications, 2007.

Katsuno T. *Dementia from the inside: how people with early-stage dementia evaluate their quality of life*. *Ageing and Society* 2005;25:197–214.

Link BG, Phelan JC. *Labeling and stigma*. [book auth.] CS Aneshensel and Phelan JC. *Handbook of Sociology of Mental Health*. Dordrecht, Netherlands: Kluwer, 1999.

Marist Poll. www.maristpoll.marist.edu/1114-alzheimers-most-feared-disease/. Accessed on March 6, 2013.

National Alliance for Caregiving and AARP. *Caregiving in the U.S.: executive summary, November 2009*. www.caregiving.org/data/. Accessed March 6, 2013.

Ory MG, Hoffman RR, Yee JL, Tennstedt S, Schulz R. *Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers*. *The Gerontologist* 1999;39:177–85.

Pinguart M, Sorensen S. *Correlates of physical health of informal caregivers: a meta-analysis*. *Journals of Gerontology Series B (Psychological Sciences and Social Sciences)* 2007;62:P126–37.

Rosas SR, Kane M. *Quality and rigor of concept mapping methodology: a pooled study analysis*. *Evaluation and Program Planning* 2012;35:236–45.

Satariano WA, Guralnik JM, Jackson RJ, Marottoli RA, Phelan EA, Prohaska TR. *Mobility and aging: new directions for public health action*. *American Journal of Public Health* 2012;102(8):1508–15.

Schulz R, Martire LM. *Family caregiving of persons with dementia: prevalence, health effects, and support strategies*. *American Journal of Geriatric Psychiatry* 2004;12:240–9.

Talley RC, Crews JE. *Framing the public health of caregiving*. *American Journal of Public Health* 2007;97:224–8.

The Concept System® Global MAXTM. Build 2012.243.13. Web-based Platform. Concept Systems, Incorporated, 2012. Browser based statistical platform, www.conceptsystemsglobal.com.

Thies W, Bleiler L. *2013 Alzheimer's disease facts and figures*. *Alzheimer's and Dementia* 2013 Mar;9(2):208–45.

Trochim W. *An introduction to concept mapping for planning and evaluation*. *Evaluation and Program Planning* 1989;12(special issue):1–16. www.socialresearchmethods.net/research/epp1/epp1.htm. Accessed March 6, 2013.

U.S. Department of Health and Human Services. *National plan to address Alzheimer's Disease*. 2012. www.aspe.hhs.gov/daltcp/napa/NatPlan.shtml. Accessed March 6, 2013.

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. *Healthy People 2020. Dementias, Including Alzheimer's Disease*. Washington, DC.; 2013a. www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=7. Accessed April 19, 2013.

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. *Healthy People 2020. Older adults*. Washington, DC.; 2013b. Available at www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=31. Accessed April 19, 2013.

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. *Healthy People 2020. Public health infrastructure*. Washington, DC; 2013c. Available at www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=35. Accessed April 19, 2013.

U.S. Department of Health and Human Services, Office of Minority Health. National Partnership for Action to End Health Disparities. *The National Plan for Action Draft as of February 17, 2010. Chapter 1: Introduction*. www.minorityhealth.hhs.gov/npa/templates/browse.aspx?&lvl=2&lvlid=34. Accessed March 6, 2013.

U.S. Department of Health and Human Services. *DHHS Action Plan to Reduce Racial and Ethnic Health Disparities*. 2011. www.minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf. Accessed April 22, 2013.

U.S. Department of Health and Human Services, Public Health Service. *The public health workforce: an agenda for the 21st century. A Report of the Public Health Functions Project*. 1997.

Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG, et al. *The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial*. *Annals of Internal Medicine* 2006;145(10):713–26.

Voisin T, Vellas B. *Diagnosis and treatment of patients with severe Alzheimer's disease*. *Drugs and Aging* 2009;26(2):135–44.

Wagster MV, King JW, Resnick SM, Rapp PR. *The 87%: guest editorial. Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 2012;67(7):739–40. doi:10.1093/gerona/gls140.

Xu J, Kochanek KD, Sherry L, Murphy BS, Tejada-Vera B. *Deaths: final data for 2007*. *National Vital Statistics Reports*. Hyattsville, MD: National Center for Health Statistics, 2010.



The actions in this Road Map provide a solid foundation for the public health community to anticipate and respond to emerging innovations and developments. By strengthening the capacity of public health agencies and leveraging strong state and national partnerships, cognitive health and impairment can be incorporated into ongoing public health efforts at national, state, and community levels.



Disclaimer

The findings and conclusions in this report do not necessarily reflect the official position of the Centers for Disease Control and Prevention or the affiliated institutions of any of the contributors. Use of trade names is for identification only and does not imply endorsement by any of contributors' institutions. Links to non-federal government organizations found in this document are provided solely as a service to the reader. These links do not constitute an endorsement of these organizations or their programs by CDC or the federal government, and none should be inferred. CDC is not responsible for the content of the individual organization sites listed in this document.



Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention, as the sentinel for the health of people in the United States and throughout the world, strives to protect people's health and safety, provide reliable health information, and improve health through strong partnerships. CDC's mission is to promote health and quality of life by preventing and controlling disease, injury, and disability.



Alzheimer's Association

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's.