Recent studies have pointed to the large and increasingly complex issues surrounding dementia in American society in general and health care in particular. The initial foray into the federal policy arena, the National Alzheimer’s Project Act, is a good first step but remains limited in scope and resources. Seeing the need for greater effort, thirty-three states have convened advisory groups and published their own plans for coordinating state-level activity to address Alzheimer’s disease across service systems. This article examines the current federal and state policy statements on dementia-related issues and offers an outlook and suggestions for next steps along with the imperative for action on a significant scale. This is necessary to address issues in a meaningful way today instead of simply holding out hope for a treatment or cure in the future. Dementia in general and Alzheimer’s disease in particular affect individuals and every facet of families, health care, business, states, and communities. While public policy statements at all levels call for increased coordination of resources, better communication, awareness, and essential linkages, more effort is required.

In more than twenty-five years of public service, I have participated in many discussions about what can be done to address Alzheimer’s disease and how to improve support for caregivers on the local, state, and national levels. These conversations often drift from what is currently known about Alzheimer’s disease to the inevitable focus on the need for more research to find effective treatments, a cure, or both.

These discussions and conversations have played out repeatedly across the United States, leading to calls for planning and action. Many factors motivate these calls, among them: an aging population; the large number of people impacted by this disease (five million people with the disease and three times that number of caregivers); multiple projections that by 2050 the number could triple; the length of time a person lives with Alzheimer’s disease and how his or her care needs change during that time; a recent Marist Institute poll that indicates Alzheimer’s is the most-feared disease in America—with the level of fear progressing with age; the health and mental health of caregivers who deal with chronic stress and many other challenges; a recent Behavioral Risk Factor Surveillance System report that more than 80 percent of those who self-report memory issues have not spoken with their health provider about it and that about 35 percent of those experiencing memory decline live alone; dramatic disparities in disease impact related to race, sex, education level, and socioeconomic status; the cost to business (estimated in the 2013 Alzheimer’s Disease Facts and Figures at $26 billion in lost productivity of caregivers alone); and the eye-opening system cost of $210 billion for 2012 alone.
Legislative Agendas

National Initiatives
The good news on Alzheimer’s disease is that progress is beginning. One important step in the right direction is the National Alzheimer’s Project Act signed into law by President Barack Obama on January 4, 2011. The act calls for relevant federal agencies, caregivers, health care providers and researchers, and state public health officials to work together through a National Alzheimer’s Advisory Council on Research Care and Services to assess the current state of care and develop recommendations to address gaps and opportunities. Following a series of meetings in 2011 and 2012, the council issued recommendations in May 2012, many of which were included in the National Plan to Address Alzheimer’s Disease issued by the Department of Health and Human Services in May 2012. This plan included the aggressive goal of finding an effective treatment by 2015; identifying addressable gaps in long-term services and supports; and pointing to quality of clinical care issues including the need for earlier and more accurate screening and diagnostics as well as treatment at every phase of the disease. The 2013 plan update identifies metrics to assess progress on all the goals; recognizes progress in such areas as education of health care professionals and research coordination; and calls for renewed efforts across the key focus areas of research, care, and services.

A second important national policy activity is the Healthy Brain Initiative, a project led by the Centers for Disease Control and Prevention and the Alzheimer’s Association. The initiative has been working for more than five years to connect state public health agencies, state and local aging services, and other human service entities. The 2013 release of the initiative’s Public Health Roadmap for State and National Partnerships is replete with concrete objectives and strategies designed to “move the needle” on these issues.

This movement for national policy embodied in the US law, national plan, and Healthy Brain Initiative focuses on where action is most needed: long-term services and supports including system linkages, education, and workforce development; improvements in prevention and clinical care including early detection, effective management of co-occurring conditions, and appropriate referrals; and meaningful growth in all aspects of research. A review of the history of addressing major public health issues reveals that all three of these elements are essential to achieving progress against any public health threat. Other important factors include strong national and state leadership and a grassroots understanding of the reality and scope of the public health issue. Alzheimer’s disease is an important health issue—some would say a health crisis—and hits at the core of our values by its social, economic, community, and family implications.

Unlike many other chronic conditions, Alzheimer’s disease carries a unique set of challenges. Custodial care, nutrition, safety, wandering, housing, and lack of judgment are just a few of the challenges that are not experienced by the typical adult with, say, hypertension or diabetes. The unique nature of Alzheimer’s disease presents a significant challenge to policy makers at the local, state, and national levels. While policy makers talk often of breaking down silos between health care stakeholders in order to create efficiencies and reduce duplication, Alzheimer’s is one condition where resources from many silos are required for patients and caregivers to maximize health and quality of life.

The national policy movement recognizes the challenges posed by Alzheimer’s disease and begins to address them by calling for leadership; resources; and partnerships in research, clinical care, and long-term services and supports. But more needs to be done.

There is a growing body of evidence pointed at preventing Alzheimer’s disease and for the value of nonclinical health-promoting activities that also address cardiovascular and diabetes risk. Strong evidence also exists for how to best support caregivers and for more effective early detection and clinical treatment. For example, the NYU Caregiver Intervention, developed by Mary Mittelman and colleagues, has been shown to dramatically delay nursing home placement of people with dementia. As is often the case, our policies, public information, workforce education, and resource allocation are struggling to catch up with the state of knowledge.

Progress In The States
State governments have begun to make some headway in the Alzheimer’s disease arena. Thirty-three states have developed and updated Alzheimer’s disease plans over the past decade. The plans reflect the need to coordinate across service systems including health, aging, social services, transportation, and others as well as to identify gaps in service and opportunities.

Plans developed by early-adopter states such as New York and California contain elements considered by many in the field to represent best practices. These elements were developed with significant input from people in the early stages of the disease, family members, caregivers, researchers, among many other stakeholders. They feature several common focal points that have since been reflected in both the Healthy...
Many state plans call for and highlight the value of earlier detection of Alzheimer’s disease.

Brain Initiative Roadmap for State and National Partnerships and, importantly, the national plans. For example, plans from New York and California include sections on public awareness, acknowledging the role and needs of caregivers, and the growing body of work on brain health or promotion of lifestyle interventions that maintain or improve brain health and typical comorbidity conditions. The plans also include recommendations to address gaps and obstacles. In addition, these state plans recognize the lack of solid information and widespread availability of misinformation, both of which are obstructions to good policy.

Many state plans call for and highlight the value of earlier detection of Alzheimer’s disease. For example, to exercise autonomy while he or she retains the capacity to do so helps not only the patient, but the family and the provider. Having the opportunity to plan for predictable challenges in health care, housing, safety, custodial care, and other key aspects of life can reduce stress on caregivers and also relieve the patient, but the family and the provider. Having the opportunity to plan for predictable challenges in health care, housing, safety, custodial care, and other key aspects of life can reduce stress on caregivers and also relieve the patient, but the family and the provider. Having the opportunity to plan for predictable challenges in health care, housing, safety, custodial care, and other key aspects of life can reduce stress on caregivers and also relieve the patient, but the family and the provider. 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Additional Issues

Training and Workforce Development

Governmental and advocacy groups have long identified training and workforce development as being critical to addressing the needs of those with Alzheimer’s and their caregivers. The spectrum of pre-service and in-service training needs runs from people assisting with activities of daily living to medical specialists in the identification and treatment of the disease. Standards for training and certification vary widely across the country, and there is a need for some standardization to address best practices and quality assurance objectively. This is a particular concern with Alzheimer’s because staffing turnover has been shown to cause complications. For example, a change to a caregiver who has a different style or approach to care may exacerbate symptoms of confusion, which may cascade to additional symptoms and further cognitive decline. Although achieving best practices and quality assurances are worthy goals, many if not most states face organizational and financial barriers to doing so.

Long-Term Services and Supports

For many policy makers and advocates, long-term services and supports are at the heart of the service system needed to address Alzheimer’s. The vast majority of long-term services and supports take place at home and in the community, are informal, and are provided either directly or paid for by family or other informal arrangements. According to the AARP Caregiver Resource Center, the list of issues facing informal caregivers is
Long-term services and supports are at the heart of the service system needed to address Alzheimer’s.

Medicaid pays for substantial amounts of care, while private long-term care and other private insurance pays for a smaller proportion of care. Because almost everyone prefers to remain at home as long as it is safe and possible, assuring the continuity of care is an important component of any policy initiative. In many instances, the decision to stay at home may not be in the hands of those closest to the patient because of resource considerations. For example, in some parts of the country, home and community-based services include a number of options between living at home and living in an institutional setting. But in many other parts of the country, institutional care remains the primary option available. Policy makers and state and federal officials face financial and other challenges to expand care to assisted living, adult homes, and similar facilities and assuring that these environments are safe and healthy. For institutional care, there remains an important public responsibility to ensure quality and safety including focus on best practices; use of nonpharmacologic interventions; and limitation of intra- or inter-facility transition, active management of comorbid conditions, and promotion of health.

Emergency Preparedness Recent events around the nation, such as Hurricane Sandy, are reminders that all Alzheimer’s policy initiatives should consider safety and emergency preparedness. This policy area has two major facets. First, it is necessary to have a well-trained corps of first responders who understand the unique issues of dementia and have practices and policies in place to respond to events such as patient wandering. The first responders’ practices and policies should encompass delivering care with respect for the Alzheimer’s patient and family as well as assuring the safety of all concerned. Second, emergency preparedness needs to be increased to respond to natural disasters or other tragedies with a particular focus on the unique needs of people with Alzheimer’s disease. For example, training shelter staff on the basics of Alzheimer’s, having backup plans for care when usual caregivers can’t access the patient, and assuring that other medical or custodial responsibilities are met can mean the difference between discomfort and tragedy in the case of emergency.

Legal and Ethical Issues Policy makers and lawmakers need to address their particular legal and ethical issues. By definition, these vary, but it is important that policies at every level reflect the evidence base of science as well as basic principles of ethics in research and practice. In the research arena, major goals have been established by national plan, and, along with the addition of some federal resources, these can form the basis of accelerated efforts. As evidenced by the growing number of state plans focused on multiple service systems, work is becoming more coordinated than ever, creating an environment where duplication is minimal and progress can be optimized. From a policy perspective, this represents major progress.

Accurate and Complete Information Planning for the future requires accurate and complete information for policy makers and the public to understand the complexity and magnitude of the issues related to Alzheimer’s disease. Much work remains in terms of the amount and manner in which population-based data are collected about Alzheimer’s disease. For example, the recent Alzheimer’s Disease Facts and Figures report points to significant data issues in mortality reporting from state to state. High-quality data in the form of vital statistics and population surveillance such as the Behavioral Risk Factor Surveillance System are a prerequisite to informed national and state policy decisions.

Leadership and Cooperation Many current policy documents address the structure of government response to Alzheimer’s disease. It appears that the most important components of this area are strong leadership and participation by all related entities, including the state-level agencies responsible for health, Medicaid, aging, mental health, education, labor, and others. Participation by each of these agencies is important to address the unique set of impacts dementia has on the lives of people with the disease, their families, and communities.

Conclusion The concepts discussed above represent a clearly daunting set of tasks to carry forward. Yet we must carry these forward with a robust effort.
We know enough now to realize that there is much we can do today, and more we must be prepared to do tomorrow. In many of the conversations I referenced in the introduction, colleagues have expressed the fear that whatever we do will be too little or too late. One of the definitions of effective public policy is that the policy is appropriately scaled to address the issue or problem at hand. When we absorb the work of scientists on early detection, prevention, treatment, or cures; the views of advocates on this issue; recent attention being given by the networks (HBO and NBC) and national media (The New York Times’ New Old Age blog); professional contacts; and our own experiences, we may see our way clear to identify the scale of resources necessary to address Alzheimer’s disease: the public health priority for today and tomorrow.

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NOTES

1 Home Instead Senior Care. Americans rank Alzheimer’s as most feared disease, according to new Marist poll for Home Instead Senior Care [Internet]. Omaha (NE): Home Instead Senior Care; 2012 Nov 13 [cited 2014 Feb 14]. Available from: http://www.homeinstead.com/News/Pages/Article.aspx?Filter1Field=ID&Filter1Value=99


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