

## Conclusion

# Improving Care Through Public Policy

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Without the development of a disease-modifying biomedical therapy, the number of people aged 65 years and older with Alzheimer's dementia may nearly triple, from 5.5 million to a projected 13.8 million, by 2050 (Alzheimer's Association, 2017). It is imperative that society be able to care for them. The practices featured throughout this supplement are just a few of the effective, individualized care models that can meet the needs and preferences of persons living with dementia, but more are required. We must be able to test, improve, and expand existing models and develop new ones.

Policy can be a powerful driver of this expansion and innovation. Promotion of standards and practices by the federal and state governments can extend the reach of high-quality care to more people in need. Indeed, with input from and robust advocacy by the Alzheimer's Association and its advocates, Congress unanimously passed the National Alzheimer's Project Act (Public Law 111–375) in December 2010, which President Barack Obama signed into law in January 2011, elevating Alzheimer's to a national policy priority.

This law required the creation of a strategic plan, the National Plan to Address Alzheimer's Disease ("National Plan"), to improve care, support, and treatment (U.S. Department of Health and Human Services, 2016). It is organized around five goals, two of which specifically address care and support: Enhance Care Quality and Efficiency (Goal 2) and Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families (Goal 3). The other three goals focus on research, public awareness, and progress of the National Plan. Various strategies and objectives were established to achieve Goals 2 and 3, spanning issues from workforce to education to care planning. Several of these are discussed in this article. The Advisory Council on Alzheimer's Research, Care, and Services ("Advisory Council") oversees the

implementation of the National Plan and is composed of federal agency representatives and stakeholders like patient advocates, caregivers, and voluntary health association representatives, among others. The Advisory Council submits its annual recommendations to update the National Plan to the U.S. Secretary of the Department of Health and Human Services.

To help drive the implementation of Goals 2 and 3 of the National Plan, the Alzheimer's Association convened a workgroup with expertise in clinical care, long-term services and supports, dementia care and support research, and public policy. Ultimately, it identified public policies needed over a 10-year period to improve systems of care and support in its *Report on milestones for care and support under the U.S. National Plan to Address Alzheimer's Disease* ("Milestones") (Borson et al., 2016). The National Plan, the Milestones, and the federal and state policy efforts discussed below can improve care and support for individuals living with dementia and their caregivers by promoting adoption and implementation of the effective practices featured in this supplement and beyond.

## Detection, Diagnosis, and Education

As has been noted, Alzheimer's and related dementias are underdiagnosed and when diagnoses are made, they are too often undisclosed by clinicians: studies suggest that fewer than half of individuals report being told of their diagnoses (Alzheimer's Association, 2015). Without detection and diagnosis, people living with dementia cannot get the help they need. Thus, education of clinicians and individuals as well as actions to improve diagnosis rates feature prominently in the National Plan and the Alzheimer's Association Milestones. Specifically, the Milestones workgroup recommends the increased use of public awareness campaigns to ensure that, by 2018, 80% of people aged 65 years and

older understand that dementia is not a normal sign of aging and are comfortable discussing memory problems with their health care providers. Furthermore, the workgroup recommends efforts to ensure that 70% of physicians are knowledgeable on the importance of detection, appropriate diagnosis, and patient disclosure by 2018; that figure should increase to 90% by 2022. Finally, both the National Plan and the Milestones devote strategies to ensure receipt of culturally sensitive education, training, and support materials. These recommendations and the policies discussed below can move us closer to the realization of these goals.

The Alzheimer's Association has long advocated for legislation to improve detection, diagnosis, and awareness of the disease. Because so many persons living with dementia are covered by the federally-funded Medicare and Medicaid programs (Alzheimer's Association, 2017), changes and improvements to these programs can have an enormous impact on beneficiaries with dementia. Although Medicare historically covered diagnostic evaluations, diagnosis cannot happen until impairment is *detected*; assessment was not a covered Medicare service. Thus, the Association offered detailed input on the creation of a new Medicare benefit under the Patient Protection and Affordable Care Act ("Affordable Care Act," "ACA") (Public Law 111-148), the Annual Wellness Visit (AWV). The AWV creates an incentive for clinicians in requiring an assessment to detect cognitive impairment. In its comments on the proposal, the Alzheimer's Association urged the Centers for Medicare & Medicaid Services (CMS) to include in the AWV assessments for safety, function, and depression; information and referrals for individuals and caregivers; and education for primary care providers on detecting cognitive impairment. The benefit went into effect in January 2011 and the Association developed guidance on how to conduct cognitive assessments to encourage utilization of the benefit by primary care providers consistent with its recommendations to CMS. This guidance, the Medicare Annual Wellness Visit Algorithm for Assessment of Cognition (Cordell et al., 2013), encourages review of patient health risk assessment information, patient observation, unstructured queries during the AWV, and suggested structured cognitive assessment tools for both patients and informants. Because the AWV remains underutilized, the Milestones workgroup has recommended identifying clinicians who have successfully incorporated the AWV into their practices and evaluating how they have increased its use as well as the cognitive assessment tools they have used. This information could, in turn, be used to increase adoption of the benefit and improve detection of cognitive impairment.

More recently, the Association, in conjunction with Congressional supporters, helped to develop the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act (S. 857/H.R. 1559), which would have created a new benefit to cover comprehensive care planning services to Medicare beneficiaries and their caregivers

following a diagnosis of Alzheimer's disease. Additionally, it would have required documentation of the diagnosis and care planning services in the beneficiary's medical record, as well as education of clinicians about the new benefit. Since its introduction in 2009, the bill saw strong bipartisan growth in the numbers of its cosponsors. In addition to advocating for the bill within Congress, the Alzheimer's Association pushed for stronger care planning efforts in discussions with CMS and before the Advisory Council, of which CMS is a member. Following that growth of bipartisan support for the HOPE for Alzheimer's Act in Congress, CMS approved a billing code, G0505, in November 2016, allowing clinicians to be reimbursed for the comprehensive assessment of beneficiaries with cognitive impairment and the development of care plans for them (Centers for Medicare & Medicaid Services [CMS], 2016). In order to bill under this code, discussed below, clinicians must provide a cognition-focused evaluation and various assessments, and the care plan must include education and support for the individual and caregivers. The implementation of this code, effective January 2017, is a significant step in improving detection, diagnosis, and education.

Other federal agencies are also taking steps to close gaps in awareness and diagnosis consistent with objectives in the National Plan. The Health Resources and Services Administration, which educates health care professionals, has coordinated the development of a unified curriculum on Alzheimer's and related dementias for primary care providers. The National Institute on Aging, the primary federal research agency on dementia, developed a portal of resources for health professionals that include tools on assessment and care management, <https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals> (National Institute on Aging [NIA], 2017). The Administration for Community Living (ACL) has developed and disseminated educational materials specific to caregivers.

Additionally, federal agencies are working to improve awareness and detection of cognitive impairment beyond the National Plan and in nonclinical settings. Effective January 2018, CMS will require home health agencies to evaluate individuals' cognitive status as part of overall patient assessments (Centers for Medicare & Medicaid Services [CMS], 2017). The National Aging and Disability Transportation Center, a program of the U.S. Department of Transportation, has published information, tips, and resources for public transportation providers on dementia and the needs of riders living with dementia (National Aging and Disability Transportation Center, 2017).

In collaboration with the Alzheimer's Association, the Centers for Disease Control and Prevention (CDC) is taking a joint federal-state approach to awareness about dementia and brain health, the Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships (Alzheimer's Association and Centers for Disease Control and Prevention, 2013). This road map outlines approaches

for state and local public health agencies and their partners to promote healthy cognitive functioning, address cognitive impairment, and meet the needs of care partners. The road map includes guidance on the development of effective policy at state and local levels. Implementation of the Public Health Road Map is a policy priority for Association chapters in the states.

Several state governments have also participated in public awareness campaigns to increase knowledge and understanding of Alzheimer's, to encourage early detection and diagnosis, and to train the general public on how to interact with persons with dementia.

- **Georgia:** In 2014, the Georgia Division of Aging Services, the Rosalynn Carter Institute for Caregiving, the Alzheimer's Association, and Georgia Public Broadcasting produced and aired "Alzheimer's: Hope For Tomorrow, Help For Today," which offered information for individuals with the disease and caregivers.
- **Oregon:** The Oregon State Unit on Aging, with a grant from the U.S. Department of Health and Human Services and matched by state and private funds, worked with the Alzheimer's Association, the Oregon Department of Human Services, and Oregon Care Partners to increase outreach, marketing, and training for staff of the statewide Aging and Disability Resource Connection (ADRC) system. Nearly all ADRC staff were trained to identify persons who may have dementia and provide appropriate information and assistance, options counseling, and care transitions.
- **New York:** The New York State Department of Health created 10 regional Centers of Excellence for Alzheimer's Disease to promote public awareness and train health care providers and students in detection, diagnosis, and treatment; to enhance the quality of dementia diagnoses; to provide comprehensive, community-based care and support; and to promote the benefits of participation in research.

These policy approaches to raising awareness about the disease, how individuals are affected by it, and encouraging detection are the first steps to connecting more people to the care and support they need.

## Assessment and Person-Centered Care Planning

Because Alzheimer's and related dementias are degenerative and lack effective treatments, care planning is essential to affected persons and caregivers. It allows persons living with dementia to participate in decision making while they are still able, and it can reduce stress and confusion for those individuals and for family and friends. It can also lead to more effective care management by clinicians, many of whom do not feel that they have the necessary time and resources to care for individuals with such complex needs (Alzheimer's Association, 2016). And because needs and

preferences can vary drastically between affected individuals and even day to day, it is all the more important that planning be tailored accordingly.

## Assessment and Care Planning

The development of individualized care plans based on comprehensive assessments remains a primary policy focus at the national and state levels. In its 2016 update to the National Plan, the Advisory Council recommended that stakeholders enhance care planning and coordination by increasing the use of person-centered and caregiver goals, and improve measurement of those goals within 3 years. The Milestones workgroup recommended reimbursement for high-quality care planning immediately following a dementia diagnosis—the crux of the HOPE for Alzheimer's Act. As noted above, CMS has realized these recommendations, now providing that reimbursement.

To receive reimbursement under billing code G0505, a clinician must provide an extensive, individualized assessment that results in a care plan (Centers for Medicare & Medicaid Services [CMS], 2016). Specifically, the encounter must include:

- Cognition-focused evaluation including a pertinent history and examination;
- Functional assessment (e.g., Basic and Instrumental Activities of Daily Living), including decision-making capacity;
- Use of standardized instruments to stage dementia;
- Medication reconciliation and review for high-risk medications, if applicable;
- Evaluation for neuropsychiatric and behavioral symptoms, including depression, including use of standardized instrument(s);
- Evaluation of safety (e.g., home), including motor vehicle operation, if applicable;
- Identification of caregiver(s), caregiver knowledge, caregiver needs, social supports, and the willingness of caregiver(s) to take on caregiving tasks;
- Advance care planning and addressing palliative care needs, if applicable and consistent with beneficiary preference; and
- Creation of a care plan, including initial plans to address any neuropsychiatric symptoms and referral to community resources as needed (e.g., adult day programs, support groups); care plan shared with the patient and/or caregiver with initial education and support.

Physicians, physician assistants, and certain advanced practice nurses are eligible to bill under this code. To ensure robust use of the code, particularly by primary care practices who may not be equipped to meet the extensive assessment requirements, the Alzheimer's Association developed the Cognitive Impairment Care Planning Toolkit ([alz.org/careplanning](http://alz.org/careplanning)) containing suggested assessment tools and other resources that are applicable in primary

care settings. As of January 2018, the temporary G0505 code will transition to 99483 and the Advisory Council has recommended that CMS should annually report code data by state, region, and diagnosis. Implemented and communicated effectively, this policy achievement will have a profound, positive impact on thousands of beneficiaries and clinicians.

### Person-Centered Planning

Although not a new concept, the fusion of person-centered care planning into state and federal policy is relatively recent and extends to individuals with a wide range of conditions and across the care continuum. Notably, Section 2402(a) of the Affordable Care Act requires states receiving federal funds to develop home- and community-based services (HCBS) that are person-centered and maximize independence and self-direction.

Recognizing the growing population of Medicare and Medicaid beneficiaries with a range of chronic conditions, including dementia, CMS has made significant changes to incorporate beneficiaries' needs and preferences into their care. In an overhaul of its regulation of long-term care facilities serving Medicare and Medicaid beneficiaries, CMS added to existing care planning requirements, directing nursing facilities to complete either a baseline care plan or a comprehensive care plan within 48 hr of admission ([Centers for Medicare & Medicaid Services \[CMS\], 2016](#)). Care planning must account for beneficiary goals, physician orders, therapy and social services, and discharge assessment and planning, among other areas. Finally, the interdisciplinary team must include participation of beneficiaries and their caregivers.

CMS and ACL have also engaged in a sweeping revision of the philosophy underpinning HCBS programs. In 2014, CMS updated its regulation governing Medicaid HCBS with an emphasis on person-centered planning, choice, self-determination, and community living. Several states serve persons with dementia through Medicaid waiver programs and raised questions on how to comply with the new rule. In response, CMS and ACL released guidance on wandering, discussed in detail below, and how facilities can employ a person-centered planning approach to ensure beneficiaries' safety, dignity, and autonomy ([Centers for Medicare & Medicaid Services, 2016](#)).

In addition to efforts to integrate the principles of person-centered planning into their HCBS programs, many states have incorporated this approach into their laws and regulations. Oregon's regulations on memory care communities are written to promote a "...positive quality of life....person directed care...dignity, choice, comfort, and independence..." ([State of Oregon, Oregon Administrative Rules, 2016](#)). They also require facilities to undergo a rigorous endorsement process that includes proof of care planning and a person-centered approach. For example, the initial application for endorsement must include a copy of the care

planning tool and employee training curricula. Facilities are also required to develop and implement life enrichment and family support programs. Staff must be trained in person-directed care and services must be delivered in "a manner that promotes autonomy and dignity...and maintain[s] or enhance[s] the resident's remaining abilities for self-care." The Commonwealth of Virginia's current Dementia State Plan includes a review by the Alzheimer's Disease and Related Disorders Commission of "all state-funded services to ensure dementia-capable approaches and policies based on principles derived from the Person-Centered Care and Culture Change movements" ([Commonwealth of Virginia Alzheimer's Disease and Related Disorders Commission, 2015](#)).

Given the unique nature of dementia and how individuals experience the disease, assessments and care plans can improve the quality of life for affected persons and their caregivers. While those assessments and care plans must be tailored from person to person, the broad dissemination of policies promoting such an approach can help to reach more people in need.

### Care Delivery, Coordination, and Transitions

The care needs of individuals living with dementia are complex. Alzheimer's and dementia can lead to memory loss, disorientation and confusion, and mood and behavior changes, all of which worsen over time. These compound the challenges of managing other health issues: Medicare beneficiaries with Alzheimer's disease and other dementias have twice as many hospital stays per year as other older people and they are more likely than those without dementia to have other chronic conditions ([Alzheimer's Association, 2017](#)). Their needs extend well beyond the medical: they need help with basic daily tasks and must consider safety issues like wandering. The needs of caregivers can be equally involved, as they must assist persons with dementia with these myriad tasks while trying to manage their own physical and emotional health. These challenges require specialized care that is coordinated among knowledgeable providers and across settings.

### Care Delivery

Strategy 2.A of the National Plan is devoted to building a workforce with the skills to provide high-quality care. The Milestones workgroup expands on this strategy, recommending that, after identifying state and county level workforce needs, those targets be met by 80% of states and counties by 2025 ([Borson et al., 2016](#)). The workforce must also be adequate and well-trained within the many settings in which persons with dementia receive care: their own homes through home health agencies, adult day care centers, assisted living facilities, hospitals, nursing homes, and hospice. Staff must also be attuned to the cultural values and preferences of different races, ethnicities, and

populations that are disproportionately affected by various forms of dementia.

The use of hospice continues to increase among persons with dementia. Nearly half are in hospice care at the time of death, yet less than half of surveyed nursing homes have a palliative care program. Palliative care can improve quality of life, control costs, and enhance patient and family satisfaction. As the demand for hospice and palliative care grow, so does the need for an adequately trained workforce. First introduced in the 114th Congress, the Palliative Care and Hospice Education and Training Act (S. 693/H.R. 1676) would increase palliative care and hospice training for health care professionals through grants and career development awards, launch a national campaign to inform patients and families about the benefits of palliative care, and expand research on the delivery of palliative care.

Efforts to deliver more person-specific care have also escalated in residential settings. In its 2016 revision of the rules governing long-term care facilities, CMS now requires that long-term care providers assess their facilities, their populations, and the workforce necessary to meet the increasingly diverse needs of residents. Because so many nursing facility residents have some form of dementia, CMS also put in place particular provisions to improve their care. As mandated by the ACA, for example, CMS extended previous dementia training requirements. Dementia training will now be part of the annual in-service training of nurse aides rather than a single initial training on the topic. CMS also went beyond the mandate, requiring that all staff, contractors, and volunteers receive some dementia training consistent with their roles. Although the 12-hr minimum required under the rule to cover all in-service topics is insufficient, this is an important first step in improving care delivery in nursing facilities. This kind of training is also important to those providing care: studies show staff trained specifically in dementia care are able to provide better quality of life for residents and have increased confidence (Hobday, Savik, Smith, & Gaugler, 2010), performance (Burgio et al., 2002), and job satisfaction (Teri, Huda, Gibbons, Young, & van Leynseele, 2005).

Many individuals with Alzheimer's and related dementias prefer and are able to remain in their homes and communities, so it is important that people in the community—but who may not necessarily deliver care—understand dementia and how it affects individuals. In addition to resources like the information for public transit providers discussed above, more formal training is imperative, particularly in matters of safety. Wandering is a prominent safety issue for persons with dementia, and police are often called to assist an individual who has become lost and confused. Kevin and Avonte's Law would require the Department of Justice to award grants to state and local law enforcement or public safety agencies to develop and operate local programs to prevent wandering and to locate missing individuals with dementia or children with developmental disabilities. With advocacy by the Alzheimer's Association and other

stakeholders, cosponsorship of the bill grew significantly in the 114th session of Congress.

Well-designed settings can be as beneficial to persons living with the disease and their families as informed providers and community members. With regard to residential long-term care and adult day facilities, CMS's 2016 HCBS guidance outlines the underlying reasons for wandering and exit-seeking, person-centered planning and staff training, and highlights environmental designs that are not only intended to deter wandering, but that can reduce overstimulation and promote community engagement. In the home, the new clinician billing code from CMS requires safety evaluations of the home and driving, if applicable. Inclusion of such elements in policy signals the importance of safe, suitable environments for this population regardless of setting.

Some states have directed specific efforts to ensure culturally-appropriate care delivery. The State of Minnesota developed an online dementia training to reflect the norms and values of diverse cultural groups. Experts offer a series of training sessions to aging community and health care stakeholders on the issue. New York State's Department of Health created a fund for the Alzheimer's Disease Caregiver Support Initiative for Underserved Communities. Contractors funded under the initiative provide support for caregivers of diverse underserved populations across the state in the form of outreach, intake and assessment, referrals, education, and beyond.

## Coordination

As has been noted, the needs of persons with dementia are complex and managing them effectively requires extensive coordination among providers and across settings. Action Number 2.G.1 of the National Plan directs the Center for Medicare and Medicaid Innovation (CMMI) within CMS to evaluate and implement new models of care coordination for individuals with dementia and their caregivers. To this end, CMMI funded the UCLA Alzheimer's and Dementia Care Program under its first round of Health Care Innovation Awards. A nurse practitioner Dementia Care Manager coordinates a needs assessment and connections to community-based organizations, creation and revision of care plans, and 24-hr access to assistance in order to maximize patients' function, independence, and dignity; to minimize caregiver strain and burnout; and to reduce unnecessary costs. This program has continued to succeed beyond the CMMI funding. Additionally, the Johns Hopkins University Maximizing Independence at Home (MIND) model, known as MIND at Home, was funded under the second round of CMMI Health Care Innovation Awards. Seeking to systematically address the barriers to persons with Alzheimer's remaining in their homes, interdisciplinary teams link patients with community health agencies, medical providers, and community resources in the Baltimore area. CMMI should continue to

test dementia-focused demonstration projects so that those deemed effective can be disseminated nationwide consistent with the National Plan's objectives.

### Transitions

Individuals living with dementia often move between nursing facilities, hospitals, and home (Callahan et al., 2012). In fact, Callahan and colleagues found that persons with dementia not only transition frequently between settings, but also experience more transitions than those without dementia. Furthermore, persons with dementia have increasing difficulty processing new information and stimuli, and disruptive situations like transitions can cause anxiety and agitation. For these reasons, the National Plan and the Milestones each devote a strategy to ensuring that people with Alzheimer's disease and related dementias experience safe and effective transitions between care settings and systems. National Plan Action Number 2.F.1 requires that CMS evaluate demonstration programs testing care transitions and Action Number 2.F.2 directs the Assistant Secretary for Planning and Evaluation, which advises the Secretary of the Department of Health and Human Services and coordinates National Plan efforts, to explore the intersection between health information technology and transitions of care. The Milestones workgroup concluded that after extensive data collection and baseline development, all preventable transitions should be reduced from the baseline by 30% by 2025.

Transitional care models featured throughout the ACA, acknowledging the relationship between transitions, care, and costs. CMS has begun to codify these practices accordingly. For example, in 2012, CMS finalized transitional care management billing codes to reimburse clinicians for the time and resources needed to orchestrate often complex transitions, and the agency continues to refine the codes to improve utilization (Centers for Medicare & Medicaid Services [CMS], 2013). It proposed the regular revision of individualized discharge plans used in hospitals and home health agencies in 2015, and the long-term care rule of 2016 makes changes to communications between providers, the types of information shared, and documentation requirements related to admissions and discharges (Centers for Medicare & Medicaid Services [CMS], 2015).

Because licensing and staffing requirements in institutional settings are regulated by state governments, state laws and regulations can influence training standards to a considerable extent. The Alzheimer's Association supports the following elements of comprehensive dementia care training for inclusion in state statutes and regulations:

- Require dementia training for all care providers employed by a facility or program in the state and who are involved in the delivery of care or have regular contact with persons with Alzheimer's or related dementias;
- Use a culturally competent training curriculum that incorporates principles of person-centered care and how to best address the needs of care recipients;
- Evaluate training through demonstration of skill competency and knowledge gained, as required by the appropriate state agency;
- Establish a system to support and enforce continuing education on dementia care;
- Allow portability of completed dementia care training across employment settings;
- Ensure trainers meet minimum requirements to qualify as instructors of dementia care curriculum; and
- Designate a state agency to formally monitor dementia training programs and ensure compliance with state dementia training requirements.

States vary significantly in their training requirements as determined by Justice in Aging in 2015 (Justice in Aging, 2015). With the support of the Alzheimer's Association, Justice in Aging surveyed the statutes and regulations of all 50 states, the District of Columbia, and Puerto Rico to determine their capability to serve the growing population of persons with dementia. Subsequently, Justice in Aging published a series of papers summarizing the results. In its final paper in the series, Justice in Aging highlighted Washington State's dementia training requirements as a model for other states, as they include multiple settings and provider types, state involvement in training content development and evaluations, detailed training objectives, demonstrated mastery of competencies, and continuing education (Justice in Aging, 2015). Similar efforts to use state-level public policy levers can improve and expand training and ultimately result in better care.

### Conclusion

Public policy is playing an increasingly prominent role in improving dementia care and support by disseminating, promoting, and codifying the effective practices and models featured throughout this supplement and around the country. But all of these models and practices warrant more research. Like the funds that have been rightly devoted to biomedical research in pursuit of a disease-modifying therapy, policymakers should direct adequate funding to care and support research.

These practices also need greater advocacy. All types of providers from across settings should join the Alzheimer's Association and its advocates in educating Members of Congress, state legislators, and agency administrators about effective models and urge them to turn good practices into policy. The policy efforts discussed herein are not exhaustive but examples for providers and policymakers to consider, to adapt to the needs of the population and their communities, and to serve those in need of care and support today.

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