



# Wisconsin State Dementia Plan: 2019–2023



Wisconsin Department of Health Services  
Division of Public Health  
P-02241 (09/2018)

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## Executive Summary

This document presents goals and strategies that constitute a framework for the new Wisconsin State Plan for Alzheimer’s Disease and Related Dementias, known as the “State Plan.” Priorities for the State Plan were developed during a March 2018 stakeholder summit, “Wisconsin’s Journey with Dementia: Crafting New Priorities in 2018.” The 2018 Dementia Summit was co-hosted by the Department of Health Services (DHS) and The Johnson Foundation at Wingspread.

The 2018 Dementia Summit brought together key stakeholders from the dementia care system, including but not limited to family caregivers, Alzheimer’s and dementia advocacy organizations, representatives from state and local health and human services agencies, state government elected officials, clinicians, researchers, home care providers, and long-term care providers. Summit participants established high-level goals and strategies in four major categories as follows:

1. Care in the Community:
  - Increase understanding and reduce the stigma associated with a dementia diagnosis.
  - Improve and expand support and education for family caregivers of people with dementia.
2. Health Care:
  - Increase timely and accurate diagnosis by primary care providers (PCPs) to enable people with Alzheimer’s disease, related dementias, and other cognitive disorders to receive culturally tailored, high-quality treatment and support in order to maintain the highest possible quality of life.
  - Ensure that health care systems and providers are dementia-capable so that people with dementia and their families receive high-quality care in the most effective and least restrictive environment possible.
3. Crisis Response for People with Dementia:
  - Increase dementia-related knowledge and competency of crisis response professionals.
  - Develop a uniform system of dementia-related crisis response with priority on treating and managing crisis in place.
4. Facility-Based Care:
  - Ensure that people with dementia receive consistent, high-quality, and appropriate care in facilities.
  - Expand the workforce and increase training and credentialing of facility staff.
  - Create a new and adequate reimbursement structure based on acuity.



The State Plan is designed to be a five-year plan, to be implemented from 2019 through 2023 under the guidance of a small State Plan steering committee. The vision is for many more partners to serve on workgroups to carry out goals and strategies established at the 2018 Dementia Summit.

The new State Plan is a strategy for all of Wisconsin, and its success will require the involvement of community, medical, social, crisis and protective service, advocacy, and provider networks. These recommendations represent a road map to help Wisconsin improve the quality of life for the thousands of families affected by Alzheimer's disease and related dementias and to minimize the public and private costs of these devastating conditions. Whether participating in a State Plan committee or workgroup or providing quality care or support to individuals with dementia, everyone can be involved in helping create a more dementia-capable Wisconsin.

## **Background**

Alzheimer's disease and related dementias are considered a major public health crisis by the Alzheimer's Association, the U.S. Department of Health & Human Services, and the World Health Organization. According to the Alzheimer's Association, 110,000 Wisconsin residents aged 65 and older had Alzheimer's disease in 2018. Between 2015 and 2040, it is projected that the population aged 65 and older will grow by 640,000 people, an increase of 72%. This expected growth rate corresponds to similar increases in the number of people with dementia. Unless the disease and conditions that cause it can be effectively treated or prevented, it is estimated that the number of people in Wisconsin with Alzheimer's disease or a related dementia will increase to 242,000 people by 2040.

Not only do these diseases significantly affect the life of the person living with the disease, but they also have an impact on the family members and friends who serve as caregivers. Unpaid caregivers often experience significant emotional, physical, and financial stress while providing care. It was estimated that in 2017, 194,000 caregivers provided 220,000,000 hours of unpaid care, a value of \$2,785,000,000.

In 2013, DHS engaged in a department wide initiative termed the Wisconsin Dementia Care System Redesign (DHS Redesign). The effort grew out of the knowledge that Alzheimer's disease and related dementias were already straining Wisconsin's long-term care system, and that the impact could be expected to increase as the baby boom generation ages. In addition, a 2012

decision by the Wisconsin Supreme Court in the case of *Helen E.F.*, along with the work of the *Special Legislative Committee on Legal Interventions for Persons with Alzheimer's Disease and Related Dementias* in the same year, highlighted the need for a complete review of both general resources and protective placement procedures for vulnerable adults with a dementia diagnosis.

To launch a redesign of the system of dementia care in Wisconsin, DHS partnered with The Johnson Foundation at Wingspread to convene the 2013 Dementia Care Stakeholder Summit (2013 Summit). The 2013 Summit brought together key stakeholders from around the state to provide recommendations for the redesign efforts. The result was the [Wisconsin Dementia Care System Redesign Plan](#) (Redesign Plan), published in February 2014. The Redesign Plan focused on steps DHS could take, working with its many partners, to address gaps in the current care delivery infrastructure and expand community and crisis services for people with dementia. From 2014–2017, the Redesign Plan has helped guide the efforts of DHS and many partners across the state.

In the spring of 2017, DHS and a number of partners met to discuss the need for a new plan to guide the state in its continued efforts to improve care and services for people with dementia and their family caregivers. The meeting led to a decision to plan for a second stakeholder summit in 2018. The purpose of the summit would be to engage representatives of key stakeholder groups in:

- Highlighting areas of progress since the publication of the 2014 Wisconsin Dementia Care System Redesign Plan.
- Identifying areas of the 2014 plan that continue to require attention as well as new priorities for a statewide effort over the next five years.
- Determining the goals and strategies for a new five-year Alzheimer's disease and related dementias State Plan that would be implemented by partner agencies working collectively.

## **Process of State Plan Development**

In July 2017, The Johnson Foundation at Wingspread agreed to join with DHS in co-hosting a second dementia summit to be held in March 2018. During the seven-month planning period, DHS met periodically with a group of planning partners to review topics and materials. DHS and these partners also decided to conduct a pre-summit survey to obtain public comment and input on progress since the publication of the Redesign Plan in February 2014. The survey was designed to reach three distinct audiences: people who self-identify as having cognitive difficulty, people providing care to someone with dementia in their family or social group, and professionals who work with people or families living with dementia or with systems that serve

people with dementia. It included multiple choice questions as well as an open-ended question through which respondents could make recommendations, in their own words, for the focus of the new plan.

To publicize the survey, DHS posted the link on its website and shared it widely with planning partners and other stakeholders. DHS published a report with the [2018 Public Survey Results](#) and provided it to the 2018 Dementia Summit participants to help inform their discussion of priorities for a new state plan.

Capacity at the venue for the 2018 Summit was limited, which provided opportunity for in-depth discussion. Participants represented a spectrum of stakeholders, including advocacy organizations, family caregivers, community-based services providers, crisis responders, medical care and public health professionals, facility-based care providers, and DHS. The group included members of the black, Latino, and tribal communities. A complete list of Summit participants and their organizational affiliations is attached as an appendix to the State Plan.

In addition to the survey about the state's progress since the 2014 Redesign Plan was created, 2018 Dementia Summit participants received three other documents that highlighted accomplishments in the dementia care system since the 2013 Summit. The first document, [Wisconsin Dementia Care System Redesign: Reflecting on the Accomplishments, P-01555](#), highlighted DHS's progress on achieving the goals of the Redesign Plan during 2014 and 2015. The second document, [Wisconsin Dementia Care System Redesign: Accomplishments in 2016 and 2017, P-02092](#), followed up with a description of some of the successes in 2016 and 2017. The third document comprised submissions from partner agencies that reflected key accomplishments in recent years from the network of the state's dementia and aging professionals.

During the morning of the first day of the 2018 Dementia Summit, participants reviewed the accomplishments documents and the pre-summit survey results to set the stage for key initiatives to be considered for the new State Plan. In the afternoon, participants worked in small groups to develop goals under four broad categories: care in communities, health care, dementia-related crisis response, and facility-based care. During the second day, Summit participants split into groups defined by the four categories to develop strategies under each of the goals. These discussions led to the development of the nine priority goals and 38 strategies, presented below, that would form the basis of the new State Plan.



## Priorities

### Care in the Community

**Goal #1: Increase understanding and reduce the stigma associated with a dementia diagnosis.**

#### STRATEGIES:

1. Develop tools and materials to support education and awareness about dementia.
2. Develop a public awareness campaign about dementia, highlighting the services and resources available to support people with dementia and their family caregivers.
3. Develop materials for community partners to help expand dementia-friendly community efforts, including dementia-friendly business training.
4. Expand the use of the brain health curriculum in schools.



**Goal #2: Improve and expand support and education for family caregivers of people with dementia.**

#### STRATEGIES:

1. Conduct focus groups with caregivers to better understand what they need.
2. Expand access to and the diversity of support groups for caregivers, including peer mentoring.
3. Expand access to respite care.
4. Expand the aging and disability resource center (ADRC) dementia care specialist program statewide.
5. Work with employers to support employees who are caregivers.

### Health Care

**Goal #3: Increase timely and accurate diagnosis by PCPs to enable people with Alzheimer's disease, related dementias, and other cognitive disorders to receive culturally tailored, high-quality treatment and support in order to maintain the highest possible quality of life.**

#### STRATEGIES:

1. Provide PCPs with clinical training and ready access to educational resources on standardized approaches to diagnosis and manage common cognitive disorders and on appropriate referral strategies to dementia specialists for people with complicated or rare cognitive and/or behavioral disorders.

2. Provide incentives for PCPs to appropriately diagnose dementia, mild cognitive impairment, and other cognitive disorders.
3. Provide dementia education and information on workforce needs to undergraduate students interested in health care; medical, nursing, and physician assistant students and residents in



primary care (internal medicine, family medicine) and other related fields (psychiatry, neurology) through partnerships with state medical schools, advanced practice provider training programs, and residency programs.

4. Ensure PCPs have the knowledge of and access to resources so that they may provide information to people with dementia and family caregivers to help link them with community resources.

**Goal #4: Ensure that health care systems and providers are dementia-capable so that people with dementia and their families receive high-quality care in the most effective and least restrictive environment possible.**

**STRATEGIES:**

1. Develop and implement strategies for marketing and building awareness of the value of having dementia-capable health systems for health care professionals, including administrators, associations, and the community.
2. Develop a roadmap and toolkits for role-specific dementia training for health system professionals, support teams, and administrative leaders, including:
  - a. Nonclinical staff.
  - b. Clinical staff.
  - c. Allied health professionals.
  - d. Primary care providers.
  - e. Memory care specialist clinicians.
  - f. Other clinical providers (for example, orthopedic surgeons, gastroenterologists).
  - g. Health care system administrators and leaders.
3. Enhance the competence of health care professionals by implementing basic and continuing interdisciplinary training with mandatory minimum standards.
4. Develop and incentivize the use of best practices in dementia care, including the provision of linkages to community resources and incorporation of dementia-friendly design principles and environments in health care settings.



## Crisis Response for People with Dementia



**Goal #5: Increase dementia-related knowledge and competency of crisis response professionals.**

### STRATEGIES:

1. Develop dementia-related educational materials, including decision trees and protocols that are customized for professional groups within the crisis system.
2. Create an action plan for dementia-related training for law enforcement professionals and first responders.
3. Develop a dementia-related resource database and referral system that can be localized.
4. Provide for cross-training of county adult protective services (APS) and crisis teams on dementia-capable response.

**Goal #6: Develop a uniform system of dementia-related crisis response with priority on treating and managing crisis in place.**

### STRATEGIES:

1. Develop recommendations for statutory and regulatory clarification or changes.
2. Form a statewide workgroup to develop best practices and replication procedures and guidance.
3. Develop protocols for identifying individuals at risk related to dementia and for intervening, with culturally appropriate considerations at every stage.
4. Establish an infrastructure for dementia-related crisis response, including:
  - a. Securing funding for local personnel.
  - b. Creating new positions to ensure statewide leadership within DHS.
  - c. Collecting data on system operations and analyzing to evaluate and improve.

## Facility-Based Care

**Goal #7: Ensure that people with dementia receive consistent, high-quality, and appropriate care in facilities.**

### STRATEGIES:

1. Identify and promote standards of practice for memory care and other dementia care in facilities.
2. Ensure that facility staff have the training and support needed to provide care that is consistent with standards.
3. Ensure that consumers have the information they need to make informed decisions.

4. Ensure managed care organizations (MCOs), ADRCs, and other referral services have the information needed to help consumers make informed decisions.
5. Promote and sustain the Wisconsin Coalition for Collaborative Excellence in Assisted Living (WCCEAL).

**Goal #8: Expand the workforce and increase training and credentialing of facility staff.**

**STRATEGIES:**

1. Expand health care charter schools.
2. Increase and expand outreach to high schools and middle schools to incorporate health care professions in career options for students.
3. Provide more geriatric training at secondary education level.
4. Create synergies across state agencies to ensure coordination and create efficiencies related to long-term care career development.

**Goal #9: Create a new and adequate reimbursement structure based on acuity.**

**STRATEGIES:**

1. Establish reimbursement models to recognize dementia-related costs.
2. Reimburse based on the expertise of the staff providing care and the qualifications of the facility (tied to standards).
3. Explore reimbursement for bed-holds to promote continuity.
4. Modify the long-term care functional screen and the pre-admission screen and resident review to collect information about dementia-related behaviors so that rates can be set more accurately.

## **Implementation Structure**

The final hours of the 2018 Summit were devoted to a discussion of next steps in developing and implementing the new State Plan. The meeting concluded with Summit participants agreeing that State Plan implementation would be guided by a small volunteer workgroup, the Dementia State Plan Steering Committee (Steering Committee). Summit participants volunteered to serve on the initial Steering Committee, which would be tasked with developing operating procedures and creating work groups to carry out priorities under the new State Plan.

The initial meeting of these volunteers was held in June 2018. Those in attendance felt that the small Steering Committee of approximately 10 members should begin implementing the State Plan by forming active, effective workgroups to represent the diversity of stakeholders in the state. Based on that discussion, a goal was set to keep membership on the Steering Committee at approximately 10 members. The resulting State Plan Steering Committee, consisting of a

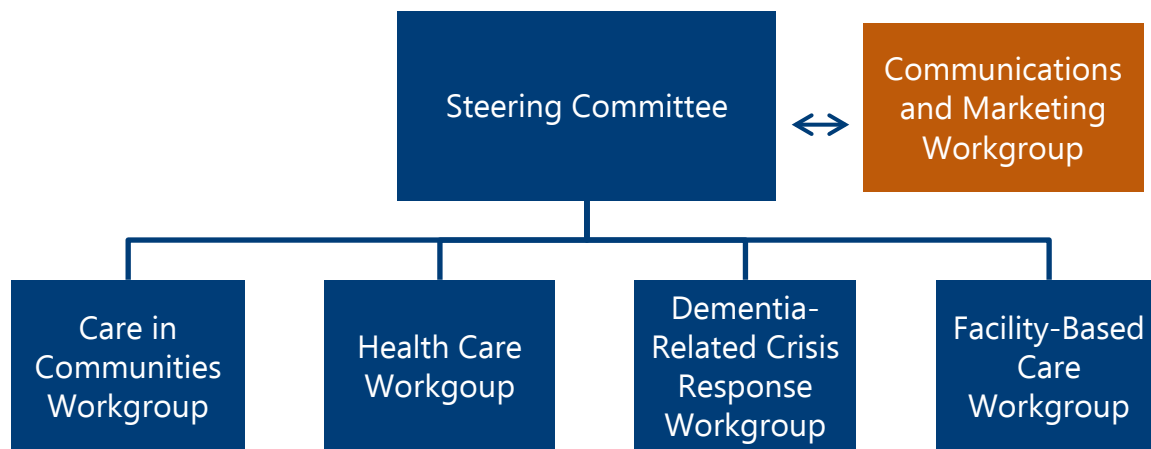
subset of these volunteers, agreed to meet on a regular basis, starting in September 2018, to establish and coordinate the efforts of work groups, monitor progress of plan implementation, develop outcome measurement tools, foster connections and collaboration within workgroups and with stakeholders throughout the state, and address barriers and critical issues.

As shown in Figure 1, the State Plan calls for five workgroups: one for each of the categories of goals established at the Dementia Summit (that is, care in communities, health care, dementia-related crisis response, and facility-based care) and a communications and marketing workgroup. Workgroup members are responsible for developing workplans in support of the goals and strategies identified at the Summit, including high-level timelines and approaches for engaging with partners across the state and accomplishing stated objectives.

The list of Summit participants in the appendix to the State Plan also indicates those who are members of the Steering Committee.

The Steering Committee started meeting in the latter half of calendar year 2018, with an initial focus on establishing operating procedures, creating workgroups, and putting in place the infrastructure for plan implementation.

**Figure 1: 2018 Dementia State Plan Implementation Structure**



## **We Are All in This Together: Opportunities for Engagement**

Successful implementation of the priorities set forth in the Dementia State Plan will require the combined efforts of partners and stakeholders across Wisconsin. DHS wishes to express gratitude to all involved in the creation of the new State Dementia Plan, including The Johnson Foundation at Wingspread and the 2018 Summit participants, and to all who are or will be engaged in making it a success. To receive the latest news on the work of the Steering Committee and its workgroups, and to learn about opportunities to get involved, sign up for updates through DHS' Dementia Capable Wisconsin email [sign-up](#).



**Participants at the 2018 Dementia Care Summit**

## Appendix

### 2018 Dementia Summit Participants

#### Holly Audley

Assistant Administrator  
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Wisconsin Department of Health Services

#### Beth Belmore\*

Chair, Fox Valley Memory Project  
Community Care Coordinator  
Mosaic Family Health & Residency

#### Heather Bruemmer\*

Executive Director/State Ombudsman  
State of Wisconsin Board on Aging and Long Term Care

#### Cynthia Carlsson\*

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#### Chris Craggs

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#### Pam Daye

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\*Also a member of the State Dementia Plan Steering Committee

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Senator  
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**Diane Meulemans**

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**Holly Onsager**

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**Kari Paterson\***

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Alzheimer's Association of South Central Wisconsin

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**Mike Rohrkaste\***

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**Laurie Schill**

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Alzheimer's Association of Greater Wisconsin

**John Vander Meer**

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**Paula Wainscott**

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