



# Redesigning Wisconsin's Dementia Care System: A Stakeholder Summit

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Sponsored by:  
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# Acknowledgements

## Summit Sponsors

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**The Wisconsin Department of Health Services** administers a wide range of services to clients in the community and at state institutions; regulates certain care providers; and supervises and consults with local public and voluntary agencies. Its responsibilities span public health; mental health and substance abuse; long-term support and care; services to people who have a disability; medical assistance; children's services; aging programs; physical and developmental disability services; sensory disability programs; operation of care and treatment facilities; quality assurance programs; nutrition supplementation programs; and health care for low-income families, elderly, and people with disabilities.



## Summit Participants

A special thanks to all who took time from their busy lives and careers to participate in the Stakeholder Summit and contribute their knowledge and ideas. A complete list of Summit Participants appears at the end of this report.

Photographs: The cover photograph is courtesy of participant Linda Helmick. All other photographs are courtesy of The Johnson Foundation at Wingspread.

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# Executive Summary

Wisconsin had almost 120,000 residents with Alzheimer’s disease or related dementias in 2010, a number that is expected to increase dramatically over the next 25 years, due largely to the aging of the Baby Boomer generation. This knowledge, combined with a recent decision by the Wisconsin Supreme Court in *Helen E.F.* and related recommendations by a Wisconsin Legislative Council Special Committee, prompted Department of Health Services Secretary Kitty Rhoades to engage the Department in redesigning Wisconsin’s dementia care system in order to provide appropriate, safe and cost-effective care for people throughout the course of the disease.

To launch this initiative, the Department of Health Services partnered with The Johnson Foundation at Wingspread to convene a Dementia Care Stakeholder Summit that brought together 33 key stakeholders with a variety of perspectives to identify concrete ways in which the Department and its partners can work together to make Wisconsin more “dementia-capable.”

Through a structured, small group discussion process, participants identified what works and what doesn’t work in the state’s existing system of dementia care; the characteristics of an ideal system of care; strategies for making the current system more “dementia capable;” and a short list of the most critical areas for prompt intervention by the Department. Those top priorities include:

- Increase community awareness of dementia issues and of the resources available to provide support to individuals with dementia and their family caregivers.
- Expand the use of dementia care specialists and case managers to coordinate care, help with transitions, and work with individuals and their families throughout the disease process.
- Revise state regulations to allow for “safe harbors” that let facilities care for residents who engage in challenging behaviors in place with less fear of liability or regulatory penalties.
- Create fiscal and systemic incentives for best practices.
- Expand mobile crisis teams to assess and diffuse difficult situations and help avoid the need for more restrictive placement.
- Create placement facility capacity to care for people with complex and challenging behavior needs.

These recommendations are ideas that are intended to provide general guidance and have not been developed in ready-to-implement detail within this report. These priority ideas provide a starting point for further discussion, investigation, and planning that will lead to further actions by the Department of Health Services and its partners to make a “dementia-capable” Wisconsin a reality.



# Summit Process and Goals

The Summit was jointly sponsored by The Johnson Foundation at Wingspread and the Wisconsin Department of Health Services to launch an effort to improve Wisconsin's system of care for individuals with Alzheimer's disease and related dementias.

The Summit brought together representatives of key stakeholder groups with a wide variety of perspectives, including clinicians, care facility and service providers, family caregivers, advocates, law enforcement, attorneys and policy makers. Thirty-three stakeholders participated in a one and one-half day structured process, led by a professional facilitator, designed to generate ideas for the Department to build on in developing and implementing its dementia redesign initiative.

Department of Health Services Secretary Kitty Rhoades, speaking via video, told participants to think big, start from scratch, and come up with a design for the state's entire system of dementia care. She asked that participants not get hung up on details or funding, but show the Department what a dementia-capable system should look like and make key recommendations for system change.

During the first day of the Summit, participants were asked to identify characteristics of the current system of care for people with dementia, including both critical areas for change and opportunities for improvement, and then to describe what an "ideal" dementia care system would look like.

The second day of the Summit focused on developing recommendations in five areas that have been identified by the Department of Health Services as elements in the care system that will need to be addressed in its plan for redesigning dementia care. These include community capacity, facility-based long term care, crisis stabilization, emergency protective placement, and care transitions.

Several participants were asked to share information about their experience with promising practices that illustrate successful approaches in each of these five components of the dementia care system. Then, through a process of small group discussion, sharing and winnowing, participants generated a list of concrete strategies for making each of the five system components more "dementia-capable." That process generated a list of 54 different ideas. As a final exercise and culmination of the Summit activity, participants were asked to narrow the list to no more than six priority recommendations.

Results of the Summit are documented in this report. Consistent with the charge given to the group and the nature of the process followed at the Summit, these ideas are presented in bulleted form, without detailed background, explanation, or consideration of how implementation would occur. They represent the collective thinking of experienced stakeholders representing a variety of interests and perspectives on dementia care. The Department of Health Services will work with these ideas to create a system of care that is responsive to the needs of people with dementia throughout the course of the disease, promotes quality of life, provides safe places for people with challenging behaviors, and is sustainable for the State of Wisconsin.



# Why Redesign the Dementia Care System Now

The proposal to redesign Wisconsin's dementia care system was prompted, in part, by the Wisconsin Supreme Court's *Helen E.F.* decision, the Special Legislative Committee on Legal Interventions for Persons with Alzheimer's Disease and Related Dementias, and the Department of Health Services' belief that the problem of challenging behaviors exhibited by individuals with Alzheimer's disease and related dementias is best addressed within the larger context of the dementia care system as a whole.

The *Helen E.F.* decision, issued in May 2012, prohibits people with only a dementia condition from being involuntarily committed for treatment under Chapter 51 of the Wisconsin Statutes, which covers emergency detentions of individuals believed to be mentally ill, drug dependent or developmentally disabled. In response to that decision, a Special Legislative Committee was convened and recommended a series of statutory changes to create procedures for psychiatric and behavioral care and treatment for individuals with dementia under the protective placement provisions in Chapter 55. With an awareness of the growing need for dementia care in the community, as well as in institutions, the Department of Health Services proposed the alternative of seeking more broad-based solutions.

The Department requested and received permission to spend two years collecting and analyzing data, researching best practices, and developing a more comprehensive approach to dementia. Such an approach would address the needs of the large and growing numbers of people with dementia living at home and in the community and encompass early detection and intervention, crisis stabilization, and community- and facility-based long term care, as well as addressing the need for emergency protective placements.

In his welcoming remarks, Division of Long Term Care Administrator Brian Shoup noted that the country looks to Wisconsin for leadership and that the outcome of this Summit will not only shape the future of dementia care in Wisconsin, but will be looked at as an example of best practices by other states across the country.



# Overview of Dementia in Wisconsin

Approximately one out of every seven individuals age 65 and older (14%) has Alzheimer's disease or a related dementia. After age 85, the proportion of the population with dementia increases to just under half (48%). Based on these prevalence rates<sup>1</sup>, it is estimated that 120,000 people in Wisconsin had dementia in 2010. By 2035, as life expectancy lengthens and the Baby Boomer generation continues to "age," this number is projected to increase by another 82,000 people or 68%.<sup>2</sup> This is a number too large to be ignored.

Assessments of Wisconsin residents living in nursing homes demonstrate that about 40% of people residing in nursing homes have dementia.<sup>3</sup> Research indicates that the same is true for residents of assisted living facilities.<sup>4</sup> Wisconsin's population estimate includes 12,000 individuals with dementia living in nursing homes and 18,000 in assisted living facilities. However, these numbers represent only about one-quarter of the all the individuals in Wisconsin with dementia, with the remaining 75% living in private homes.

According to the statewide Behavioral Risk Factor Survey conducted in Wisconsin in 2011,<sup>5</sup> just under 10% of adult respondents of all ages reported having confusion or memory loss that is happening more often or getting worse in the last year, and another 9% indicated that at least one other adult in their household was experiencing similar confusion or memory loss in the last year. Of these, fully 75% reported that they rarely or never got help relating to their memory loss from family or friends, while only 9% always or usually got such help. Over 9,000 people with dementia receive care through the State's Medicaid Home and Community Based Services waivers.<sup>6</sup>

For a variety of reasons, many people with memory loss do not have a diagnosis of Alzheimer's disease or other dementia. Only 28% of those who reported having experienced memory loss in the Behavioral Risk Factor Survey had discussed their memory loss with a health care professional, and of those, only 15% received a diagnosis. That means that 95% of the people who said they have experienced worsening confusion or memory loss have not been diagnosed with dementia.

Between 60 and 90% of people with Alzheimer's disease will exhibit agitated behavior during the course of the disease process.<sup>7</sup> While relatively few of these people will become violent or dangerous, a small but not insignificant proportion will exhibit behaviors that are challenging enough for their caregivers such that an emergency response is warranted. Agitated behavior is the primary reason that people with dementia are placed in psychiatric institutions under Chapter 51. Yet based on *Helen E.F.*, it is not appropriate to use an emergency detention to involuntarily admit individuals with dementia to inpatient psychiatric facilities unless they also have a co-occurring mental illness. This recent development is increasing the need for alternative emergency placement capacity. In addition, it is estimated that, even

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<sup>1</sup> Dementia prevalence rates are those recommended by Denis A. Evans, M.D., et al. "Prevalence of Alzheimer's Disease in a Community Population of Older Persons," *Journal of the American Medical Association*, 262(18), 1989. Note that these rates may include individuals with or without a confirmed dementia diagnosis

<sup>2</sup> Population Projections, 2005 through 2035, from Wisconsin Department of Administration, Demographic Services Center, Vintage 2008.

<sup>3</sup> Wisconsin Department of Health Services, Division of Quality Assurance (Minimum Data Set - nursing home data)

<sup>4</sup> 2010 National Survey of Residential Care Facilities, U.S. Dept. of Health and Human Services

<sup>5</sup> 2011 Behavioral Risk Factor Survey, Centers for Disease Control and Prevention and WI Office for Health Informatics

<sup>6</sup> Wisconsin Department of Health Services, Division of Long Term Care (Medicaid Waiver data)

<sup>7</sup> Tariot, P.N. and Blazina, L. "The Psychopathology of Dementia," *Handbook of Dementing Illness* (1994): 461-475.

with strong community and residential care options with well-trained staff, a small number of individuals with dementia will engage in behaviors that are so challenging for caregivers that they will require special care over a longer period.

Without a proactive approach to improve our current system of care, the State of Wisconsin and its facilities, service providers, families and taxpayers will face growing costs and increasingly strained and inadequate resources for meeting the needs of people with Alzheimer’s disease and related dementias.



# Challenges and Opportunities

The current system of dementia care in Wisconsin involves both challenges and opportunities. Summit participants started their discussion by identifying characteristics of the current system, including areas that need improvement as well as areas that provide opportunities to build on and strengthen elements of the current system.

## Gaps and Deficiencies in the Current System

- A fragmented system of care.
- Lack of coordination between the health care and long term care systems.
- People don't know how to navigate the system.
- Families are stressed and don't know where to go for help.
- Stigma leads to people turning away; people suffer in silence.
- Dementia is often considered to be "normal aging."
- Many times, doctors cannot or do not diagnose dementia or refer patients for services. There is a feeling that because there is no cure, nothing can be done.
- Wide variation in access to services. Rural areas have less capacity for diagnosis and treatment.
- Few resources to fund or train caregivers.
- Lack of geriatricians and physicians knowledgeable about dementia.
- Over-medication of people with dementia.
- The system reacts to crises, rather than providing proactive interventions.
- Inconsistency in how emergency protective placements are handled.
- Breakdowns in communication during transitions from one part of the system to another.
- Nursing homes and assisted living facilities are viewed as "the end of the road."
- Nursing homes send challenging patients to other facilities and will not let them return.
- Risk of good facilities, those that are able to care for high needs patients, becoming "dumping grounds."
- Workforce shortages. Low pay, few benefits and lack of training for workers.
- Barriers to offering long term care for people with dementia include reimbursement, regulations and workforce issues.
- Punitive elements and perverse incentives in the system.

## Opportunities

- Education and training for the community, family caregivers, and workers.
- Philosophy and methods of person-centered care.
- Early identification and intervention.
- Looking for ways to enhance quality of life for people with dementia.
- Roadmaps for families to follow.
- Flexibility in implementing best practices and standards.
- Incentives for early intervention.
- Making dementia care profitable.
- Care transitions.
- Mobile crisis intervention.
- Avoiding blame and acknowledging that there will be mistakes.

# Defining an Ideal System of Dementia Care

Summit participants were asked to envision an ideal system of dementia care by answering the question: Where should the State be going in its effort to develop a dementia capable system of care and how will we know when we get there? The following emerged as key features of a dementia capable system of care:

## Single Point of Entry

- Accessible service delivery system – one stop, no wrong doors, person-centered, responsive.
- Single entry points for information and referral, memory screening, diagnostic testing, access to legal, financial and social assistance.
- Capacity for non-English speakers.
- Constant communication flow between single point of entry and community resources – mutual referrals.

## Community Involvement

- Public awareness, community awareness, marketing.
- Community “owns the problem,” communities are educated and feel responsible for helping.
- Churches, community centers and other community organizations are part of the solution.
- Recognize and define the role of law enforcement, Emergency Medical Systems (EMS) and first responders – people will continue to call them.
- Strategic community outreach in conjunction with nutrition, vaccination, health interventions and other organizations and activities.

## Coordinated Care Across Systems

- Support people with dementia and caregivers across entire spectrum of the disease, from preventive care through diagnosis to death.
- Integrated system of care.
- Case management: One person follows individual; “lifetime consultant” stays with person, coordinating care from diagnosis through death.
- Communication, sharing information in both directions between single point of entry, case manager, providers and health systems for the benefit of the person.
- Develop mechanisms for providing feedback.
- Statewide record-keeping, electronic medical records.
- Telemedicine and other uses of technology.
- Regionalize access to services; make access person-centered (where it makes the most sense to the person to go – not necessarily county of residence).
- Outreach and education for primary care doctors and emergency room providers.
- Address comorbidities and coordinate care across diagnostic categories.

### **Crisis Management**

- Clear legal processes in place to address immediate issues.
- Crisis prevention and intervention.
- More attention to crisis prevention in late-stage dementia where communication problems intensify.

### **Consistent Availability of Services**

- Statewide consistency in service availability (standardized expectations), with flexibility allowed for specifics of local implementation.
- Options for different types of supports and services.
- Accessible services – physically, financially, legally.
- Early detection, access to diagnostic clinics.
- Develop approaches to more effectively address early-, mid- and late-stage dementia care.
- Regional centers with multi-disciplinary teams.
- Clarify and strengthen processes and systems to get at the root of the problems.

### **Person-Centered Care**

- Person centered care, responsive to the individual, talk to family members to find out what they need.
- Care and services that are responsive to ethnic, cultural, disability, language and religious needs – inclusiveness is the key (lesbian, gay, bisexual, transgender, disability groups, race, language).
- Ability to provide home visits.
- Support for families and caregivers.
- Person- and caregiver-centered care plans.
- Non-pharmacological protocols for all patients, including those with behavioral symptoms.
- Develop standards for end-of-life care, including obtaining advance directives, “having the conversation” about prognosis and goals for care, opportunities for palliative approaches.

### **Workforce Development and Support**

- Support for all kinds of care providers (professional, paraprofessional, volunteer, family).
- Education and training for all levels of workforce and caregivers; consistent training standards.
- Appropriate pay, health care and other benefits.
- Caregivers have the tools to do the job.
- Professional development and respect for caregiving staff.
- Build workforce in all dimensions: numbers, range of specialties, prestige, self-esteem, compensation.
- Appropriate pay and benefits, commensurate with the work.
- Stigma reduction around the disease and around working with those who have the disease.
- Develop supportive systems for caregivers who are in the workforce.
- Education for employers about how to accommodate and support their caregiving workers.
- Keeping people with early memory loss in the workforce.
- Recruitment of people into the field – starting with those still in high school.
- Creating career paths for caregivers to provide opportunities for advancement.

## **Education**

- Education about the disease (signs and symptoms, brain health, prevention, prognosis; provider/caregiver training about heredity) and its impact on people's lives. Awareness of what is normal and what's not.
- Education about the resources that are available for individuals and families dealing with dementia.
- Provider/caregiver training and decision protocols to prevent situations escalating to crisis.
- Include dementia in medical school curricula.
- Training for law enforcement, EMS and first responders.

## **Fiscal and Regulatory Reform**

- Money should follow the person – people should not be constrained by geographically fixed funding.
- Create financial incentives for physicians and other health care providers to diagnose, treat, follow up and refer for services, payment that allows doctors to spend enough time with patients and families.
- Removal of regulatory disincentives for providers, facilities, families to do the right thing
- Reduce regulatory emphasis on safety at all cost to individual; make it more possible to treat in place, safe harbor for facilities.
- Consider different balance between emphases on individual rights/autonomy and safety.
- Flexibility to be responsive to individual needs.
- Resources to meet needs.
- Public policy strategies that address the public health issues related to dementia.

## **Decision Support**

- Continuous identification of evidence-based practices.
- Measurement of outcomes: data, informatics, assessment tools, quality measures.
- Use of research that measures program efficiency and effectiveness.
- A good business model.
- Alignment of incentives with other components of the system; broad incentives to support system change.



# Bright Spots: Promising Practices to Build On

Several participants were invited to share their innovations and best practices, to provide a positive point of departure for subsequent Summit activities. These “bright spots” illustrate practices the presenters have found to be successful approaches to providing quality support and services in different areas of the dementia care system, including community capacity, long term care facilities, crisis intervention, emergency protective placement and care transitions.

## **A Dementia-Friendly Community**

Sue Torum, Director, Aging and Disability Resource Center of Jefferson County

The Aging and Disability Resource Center (ADRC) of Jefferson County has organized a community-wide response to dementia, in partnership with local businesses, service providers, senior housing, the public library, law enforcement, family members, caregivers and others with an interest or concern. The effort is intended to support individuals with dementia in their homes and community through increased awareness and the efforts of local organizations, businesses and individuals.

The ADRC’s dementia care specialist organized a local dementia summit to identify issues and launch the effort, and provides outreach to increase community awareness. She also provides training on how to communicate and interact with people with dementia and appropriately respond to the kinds of situations that may arise. The ADRC provides free memory screening. It also helps people affected by dementia to identify potential sources of support, plan how to meet their care needs and address related legal and financial concerns. All ADRC and Adult Protective Services (APS) staff are certified dementia practitioners.

Other community building activities are key features of this effort. Several businesses in Fort Atkinson and Watertown, including the Fort Atkinson library, have had their employees trained and identified themselves as welcoming places that people with dementia can continue to visit as their disease progresses, in order to maintain familiar routines and support quality of life. The Sheriff’s Office has created a voluntary registry for people with dementia, so it can contact their families or caregivers if they wander off or get into problematic situations, and is implementing Project Lifesaver to electronically keep track of at-risk individuals. Mobile crisis services are currently not available in the county; however, mental health staff and several physicians who already do home visits are meeting as a group to implement an on-site emergency response.

The goal is to meet people’s needs in the community and avoid or delay the need for institutionalization. However, this is not always possible. Facilities are also an important part of the initiative and are being recruited to provide specialty care and accept Chapter 55 emergency protective placements. Two new dementia-specific community based residential facilities (CBRFs) are under construction and will provide 90 more beds. Neither of these CBRFs is a designated emergency placement facility, nor have they expressed interest. However, one nursing home has indicated an interest in becoming designated.

All this has been accomplished in less than a year and Jefferson County is well on its way to achieving its goal of becoming a “dementia-capable” community.

## **A Coordinated Approach to Dementia in a Long Term Care Facility**

Wanda Plachecki, Administrator, Lakeview Health Center, West Salem, WI

Lakeview Health Center in La Crosse County is a regional care center, most of whose residents can no longer be cared for at home or in other facilities. Lakeview takes a comprehensive approach to dementia care, beginning with the transition from the person's prior place of residence. A welcoming committee is assigned to provide staff with information about the person prior to admission and creates a "getting to know you" poster with personal history and other information provided by the individual and his or her family. Staff assignments are made so that the person sees the same faces every day – the same nurses, certified nursing assistants (CNAs), housekeepers and maintenance staff. This helps the resident feel more comfortable and gives staff an opportunity to get to know the person and be able to notice if there is a change or problem developing.

The nurses, social worker and administrator meet every morning to review the preceding 24 hours and have daily "huddles" with direct care workers to talk about how to handle specific situations with individual residents. If a resident needs more urgent care, staff communicate with the mobile crisis team in La Crosse County via phone or e-mail to get ideas about how to handle the situation and head off a crisis. Before asking the mobile crisis team to come on site or calling in the police, the staff team pulls together all the information about the person's plan and the interventions they have tried, to help avoid hospitalization. With this approach in place, Lakeview has not had to hospitalize any resident – with or without dementia – in over a year.

## **Crisis Stabilization through Serial Trial Intervention**

Christine Kovach, RN, PhD, University of Wisconsin-Milwaukee

The Serial Trial Intervention is a method to identify and treat the underlying causes of agitated and disruptive behaviors in people in the advanced stage of dementia who are non-verbal. Underassessment and treatment for pain can be a serious problem for people who are non-verbal and is the root cause of many challenging and disruptive behaviors. Disruptive behavior takes staff time, incites other residents, and is the primary reason for residents being discharged to expensive hospitals and psychiatric institutions which may not be appropriate to meet the person's needs.

Built on the premise that behavior communicates a need, the intervention requires staff to use a decision support tool and step-wise process to solve the problem. The process begins with an assessment to determine if the person has an infection, fracture or other physical cause for the behavior, followed by a decision about whether and how to treat the condition. If the behavior continues, an affective assessment is performed to identify potential sources of stress that can then be addressed by sensory stimulation, calming activities, meaningful interaction, or other changes in the environment. If the behavior continues, then comfort measures and other non-pharmacological interventions are tried. This is followed by analgesics and, if the other efforts are ineffective, then psychiatric consultation and/or psychotropic medication are used. Results obtained from implementing the method in a controlled trial in 12 nursing facilities showed significant reductions in pain, agitation, other (comorbid) medical problems, and stress hormones (cortisol) in the patient's blood. The intervention also resulted in significantly improved assessments of the patient's situation, increased staff persistence in solving the person's unmet need, and a significant increase in use of analgesics to address pain. Dr. Kovach plans to perform a similar controlled trial to test the technique in a community setting.

## **Emergency Protective Placement**

Amy Temby, APS Social Worker, Waupaca County Department of Health and Human Services

Amy Temby told the story of a person with dementia to illustrate the value of emergency protective placement and Adult Protective Services. Rachel<sup>8</sup> lived with an adult son who suffered from mental illness. The home was overrun with animals, including many that had died; the home had an overpowering odor; no running water; and the electricity had been turned off. Neither Rachel nor her son would cooperate with efforts by the APS social worker to intervene. It took law enforcement to get access to the home, where a preliminary assessment indicated that Rachel had profound dementia. Rachel had been isolated from other members of her family, and suffered from clear signs of abuse, neglect and self-neglect. She was carried out of her home under protest, in her rocking chair, and taken to the emergency room, accompanied by Amy. Ultimately, Rachel was placed in a nursing home where, with help from APS and nursing home staff, she was able to re-establish contact with her sisters and brothers and even began to play music again. Her son was charged with abuse and put on a conditional release program with a caseworker, and was able to continue to be involved with his mother in a monitored and more positive way. While APS generally starts with the goal of keeping the person in their home, in this case, Rachel did much better in the nursing home and was able to live out her life there with family connections and a noticeably better quality of life. Emergency protective placement played an essential role in getting Rachel the care and services she needed for the remainder of her life.

## **Care Transitions with a Dementia Support Team**

Rob Gundermann, Alzheimer's and Dementia Alliance of Wisconsin

The Dementia Support Team was established by Dane County Human Services in 2009 to help reintegrate residents with dementia who have been admitted to a psychiatric facility back into the long term care setting. The Team is a collaborative effort on the part of Alzheimer's and Dementia Alliance of Wisconsin, Dr. Kim Petersen, the South Madison Coalition of the Elderly, and Dane County Mental Health. Individuals are enrolled in the program by referral to a case manager at the South Madison Coalition. Alliance staff and Dr. Peterson assess the individual; obtain information from the facility, medical personnel, family members or guardians; conduct cognitive testing when needed; and develop a treatment and intervention plan. The plan includes:

- Diagnosis.
- Medication evaluation and adjustment.
- Evaluation of the facility environment, routines and staff strengths.
- Individualized interventions to minimize challenging behaviors, establish and maintain successful relationships, and create a workable environment for the person.
- An assessment of financial resources and assistance in accessing long term care benefits for those who are eligible.

Team members train staff of the long term care facility where the person is or will be residing about the person's diagnosis, the reasons for behavioral challenges, the person's strengths and life story, and strategies for implementing the intervention plan. Ongoing monitoring is provided by the social work case manager at the Coalition, and the full team is available to provide follow up, additional training and intervention as needed.

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<sup>8</sup> Fictitious name for illustrative purposes only.

The program has been highly effective in working with mental health facilities, having successfully relocated everyone who was referred during the Team’s four-year history. The first individual the Team worked with had been housed at Mendota Mental Health Institute for more than nine months at a cost of over \$1,000 a day. The Team was able to transition him to a Community-Based Residential Facility within three weeks with no further problems. Team members estimate that 75% of the people they relocate could have been treated in place, if they had received earlier intervention. The Team is now working with residential settings, to help them retain residents with challenging behaviors and avoid the impulse to “just get this person out of here.” Preventing an admission by treating the person in non-institutional settings avoids potentially unnecessary trauma and is less costly.



# Strategies for Achieving a More Dementia-Capable System of Care

Small group discussions generated the following strategies for achieving a more dementia capable system of care in Wisconsin. These strategies represent ideas generated by Summit participants in each of the five topic areas that have been identified by the Department of Health Services as system elements to be addressed in its plan for redesigning dementia care. These include: community capacity, facility-based long term care, emergency protective placement, care transitions and crisis stabilization.

## Community Capacity

1. Increase community awareness of the need for early diagnosis and resource availability by conducting a marketing campaign and expanding the ADRC role.
2. Provide prevention measures and early dementia programming.
3. Involve mobile crisis teams early on, when behaviors are manageable.
4. Take a public health approach to make effective use of resources and build on existing providers in order to scale up coordinated services.
5. Reform reimbursement to incentivize best practices in dementia care.
6. Train police and first responders on dementia and challenging behaviors, with the goal of preventing institutionalization.
7. Create community capacity to respond to crises.
8. Consistent use of screening and diagnostic tools.
9. Have a dementia care specialist/care manager work with the individual throughout the disease course.
10. Support family caregivers by providing structured caregiver support plans.

## Facility-Based Long Term Care

11. Revise assisted living and nursing home regulations to incentivize appropriate dementia care.
12. Adjust reimbursement to incentivize dementia care.
13. Provide regional facilities for residents with complex and challenging care needs.
14. Integrate long term care facilities into the community by encouraging them to offer home care services.
15. Establish uniform standards and expectations for facilities and community providers to avoid care transitions.
16. Create a “safe harbor” to allow facilities to care for residents who engage in challenging behaviors in place.
17. Create centers for excellence to expand use of best practices.
18. Use dementia care specialists to coach and mentor staff.
19. Establish an accreditation process, instead of regulation, for dementia care.
20. Incentivize facilities to build a business model that meets standards of dementia care, including payment for staff trainers and consultants to provide excellent care.

## **Emergency Protective Placement**

21. Use evidence-based practice for person centered care.
22. Create a separate statute for emergency protective placement of people with cognitive impairments.
23. Create regional mobile crisis teams, using the Wisconsin Star Method for assessment.
24. Incentivize Chapter 55 designated facilities with expertise in dementia by increasing reimbursement for emergency protective placements.
25. Change the law so that county workers can evaluate people for emergency protective placement.
26. Remove legal obstacles to getting timely emergency protective placements.
27. Have integrated teams that involve mental health, APS, county aging staff and law enforcement, any of whom is authorized to initiate a placement and all of whom are expected to work together.
28. Create regional capacity to assess and treat dementia; additional capacity is needed in rural areas especially.
29. Integrate and coordinate care provided by primary care doctors, emergency rooms and ADRCs to prevent or minimize emergency placements.

## **Care Transitions**

30. Establish community care collaborations statewide to reduce admissions.
31. Ensure transferability of medical records across the spectrum of care.
32. Use telemedicine and other technologies to improve care transitions.
33. Make care management available statewide, regardless of payer source or entry point.
34. Establish an elder court which is familiar with and able to deal with dementia, using the California model as an example.
35. Establish a single statewide call line for accessing resources.
36. Implement a standardized transition process.
37. Make dementia capable teams available to provide crisis response and care in place.
38. Have statewide resource specialists available to triage, consult on what can be done, and follow the person through the transition process.
39. Establish memoranda of understanding between providers and specialists regarding provision of support during care transition.

## **Crisis Stabilization**

40. Use person centered care plans that follow the person before, during and after crises.
41. Build capacity for mobile crisis units.
42. Improve diagnosis and assessment for people with multiple co-morbidities.
43. Use physician extenders.
44. Follow a process to admit, stabilize and then transfer people to an appropriate setting.
45. Use technology such as telemedicine smart phones and Skype to access specialty services, especially in rural areas where access is lacking.
46. Use non-police transfers, with no handcuffs or cages.
47. Expand authority for APS to offer help before starting the emergency placement process, to avoid having to go to court and possibly avoiding the need for placement.

48. Involve emergency rooms in crisis stabilization.
49. Implement a 911 response to crises involving people with dementia, to access information on a registry that could be helpful in de-escalating the situation before a mobile crisis unit is called in.
50. Use a community paramedic model to provide crisis service in the home.
51. Develop regional crisis response systems.
52. Use interveners available in the various facility and community based settings who can assess and potentially diffuse the situation. Interveners could be facility staff or mobile teams.
53. Establish more placement facilities capable of providing care in crisis situations.
54. Realize that there is “no happy ending” for everyone; provide better connections to hospice care.



# Priority Recommendations

The following is a short list of priority recommendations developed by Summit participants. These were arrived at by having each of the six small groups pick its top two or three priorities from the previously identified strategies and then post their recommendations for large group review. The facilitator then led a consensus based discussion to arrive at the final short list of strategies. The process included combining numerous strategies since they were closely related. The recommendations below have unanimous support of the planning group as the top priorities for action.

1. Increase community awareness of dementia issues and of the resources available to provide support to individuals with dementia and their family caregivers.
2. Expand the use of dementia care specialists and case managers to coordinate care, help with transitions, and work with individuals and their families throughout the disease process.
3. Revise state regulations to allow for “safe harbors” that let facilities care for residents who engage in challenging behaviors in place with less fear of liability or regulatory penalties.
4. Create fiscal and systemic incentives for best practices.
5. Expand mobile crisis teams to assess and diffuse difficult situations and help avoid the need for institutional placement.
6. Create the placement facility capacity to care for people with complex and challenging behavior needs.



## Next Steps

The Secretary of the Department of Health Services has committed the Department to shepherding a redesign of the system of dementia care in Wisconsin. The Department and The Johnson Foundation at Wingspread co-hosted the Dementia Care Stakeholder Summit for the express purpose of engaging representatives of key stakeholder groups in a collaborative effort to identify top priorities for this system redesign. Thanks to the dedicated efforts of Summit participants, enhanced by a setting that was conducive to a collective effort, this goal was achieved. The next step is for the Department, informed by the Summit priorities, to develop a “*Plan for a Dementia Capable System of Care*” to address gaps in the current care delivery infrastructure and expand community and crisis services for people with dementia. The focus of the *Plan* will be on steps the Department can 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. The timeline is short; the Department intends to share a draft of the *Plan* by the end of the year. After a period of comment by stakeholders, the *Plan* will be finalized early in 2014 and will be used to guide the work of the Department in the coming years.



# List of Summit Participants

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