



Dementia Crisis Innovation Grants

Round Two Grant Report



Wisconsin Department of Health Services
Division of Public Health
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Executive Summary

From early 2016 through 2018, the Wisconsin Department of Health Services (DHS) funded competitive grants for counties or county consortia interested in improving the dementia capability of their crisis response systems. The 18-month Dementia Crisis Innovation Grants required awardees to work collaboratively with a wide range of local stakeholders to review current crisis protocols and procedures, training needs, and resources available to support people with dementia experiencing crisis, in order to identify strengths and address shortcomings in their local capacity to deal with dementia-related crises. In addition, awardees gathered previously uncollected data and generated ideas, tools, and information to share with others in order to further efforts to improve dementia-capable crisis response statewide.

There were two rounds of grant awards. The first grants, which ran from January 2016 through June 2017, and totaled nearly \$299,000, were awarded to six recipients:

- The Aging and Disability Resource Center of the North (ADRC-N), serving Ashland, Bayfield, Iron, Price, and Sawyer counties
- The Adult Protective Services Department of North Central Health Care (NCHC), serving Langlade, Lincoln, and Marathon counties
- Dodge County
- Kenosha County
- La Crosse County
- Milwaukee County

[Improving Dementia-Related Crisis Response: Results of Six Innovation Grants, P-02327](#), a report summarizing the activities of these grantees and the lessons learned, was issued in early 2018.

The second round of funding ran from July 2017 through December 2018, and was open to new applicants as well as to applicants that received a grant in the first round of funding. Grants totaling more than \$421,000 were awarded to eight recipients. The awardees included five new recipients:

- Brown County
- Dane County
- A consortium made up of Oneida, Forest, and Vilas counties
- Polk County
- Waukesha County

There were also three Dementia Crisis Innovation Round One recipients that received funding in Round Two:

- Dodge County
- La Crosse County
- Milwaukee County

Considered together, the 14 grants awarded through the two rounds of funding went to agencies serving 19 counties and 50% of the state's population.

This report summarizes the second round of Dementia Crisis Innovation Grants as well as the lessons learned from both rounds of funding, and provides examples of dementia-related tools and resources gathered or developed by the Round Two grantees.

The Dementia Crisis Innovation Grants led to some broad observations regarding how best to approach improving the dementia capability of county crisis response systems. These include ensuring leadership to oversee the activities of the project; involving a broad-based coalition of partners; reviewing the existing policies, procedures, services, and resources of the crisis response system to determine the gaps and capacity of the system and develop an improvement plan; evaluating and planning for local training needs; ensuring a system-wide understanding of how to avoid or de-escalate dementia-related crises; creating stabilization in place supports for people with dementia; identifying residential facilities willing to accept people needing urgent placement who cannot be stabilized in place; and carrying out reviews of dementia-related crises after the fact to assess the outcome and inform program improvement efforts.

In 2014, DHS released a [Dementia Care System Redesign Plan](#) to address gaps in the dementia care delivery infrastructure, including crisis services for people with dementia. At a March 2018 summit, DHS and a number of partners developed a new five-year [Wisconsin State Dementia Plan](#) to guide continued efforts to improve care and services for people with dementia. Lessons learned through the Dementia Crisis Innovation Grants will help inform the work efforts under the state plan over the course of the next five years.

Introduction

From 2016 through 2018, DHS funded competitive grants for counties or county consortia interested in improving the dementia capability of their crisis response systems. There were two rounds of grant awards. The first grants ran from January 2016 through June 2017 and totaled nearly \$299,000. The second round of grants, which ran from July 2017 through December 2018 and totaled more than \$421,000, were awarded to eight recipients.

This report summarizes the second round of Dementia Crisis Innovation Grants as well as the lessons learned from both rounds of funding as grantees worked to improve their crisis response capacity for people with dementia. It highlights the successes and barriers that were identified by the grantees, as well as examples of tools and resources gathered or created through these grants. The report is intended to help counties and their community partners take steps to improve the state of crisis response in the best interest of those with dementia.

Background

The crisis intervention system involves a continuum of services provided to individuals experiencing a crisis who may pose an imminent risk of harm to themselves, their caregivers, or others. Crisis intervention may involve several phases. Crisis response is the immediate response to an urgent situation, involving rapid assessment of factors leading to the crisis and a determination of what needs to be done right then to intervene, de-escalate the situation, and maintain safety. Crisis response is typically provided by law enforcement, the mental health crisis unit, or the adult protective services unit. Responders may not know at first whether the person in crisis has mental illness, dementia, or some other contributing condition. Following the initial crisis response, county mental health or adult protective services units, nursing homes, residential facilities, or hospitals may provide a range of services to help stabilize the situation, improve acute symptoms of distress and impaired functioning, and address problems that led to the crisis. Certain individuals who are at risk of harming themselves or others may need to be temporarily relocated to a safe environment for ongoing care. Such care is most often provided in facilities, though some individuals may be cared for at home with appropriate support.

Wisconsin's crisis intervention system is governed by several different laws or administrative codes, applies to individuals with a range of diagnoses and conditions, and involves the efforts of a number of partners with differing roles and responsibilities. The major laws relating to crisis

intervention services, [Wis. Stat. ch. 51](#),¹ [Wis. Stat. ch. 55](#),² and [Wis. Admin. Code ch. DHS 34](#),³ are intended to protect individuals with a range of diagnoses and conditions, including people with mental health and substance use disorders, developmental disabilities, or dementia. All Wisconsin counties are required to provide at least basic emergency services to someone in crisis. In addition, most county programs are certified under Wis. Admin. Code ch. DHS 34, subch. III to provide mobile crisis services, which are designed to assess and de-escalate a crisis situation in the place where it occurs, whether in the person's home or in a facility setting.

Crisis response systems in Wisconsin vary from county to county, depending on local practices and available resources. There may be differences in terms of agency organization and relationships among partners. For example, in some counties the mental health crisis unit is in the same agency as adult protective services (APS), but in other counties these services are in different agencies. Some mental health crisis units respond to APS calls, while others typically do not. Some Wisconsin counties have highly skilled personnel and mobile crisis intervention services. In other areas, there may be little effective crisis response beyond calling 911 or the sheriff's department.

Adding to the complexity, county agencies have limited capacity to control everything that transpires during a crisis when other entities, including law enforcement, corporation counsel, the courts, guardians ad litem, family and caregivers, residential facilities, hospitals, and others, are involved. In addition, there is no single funding stream to pay for the services provided to keep a person safe.

¹ Chapter 51 governs treatment and rehabilitation services related to mental disorders and developmental disabilities and for mental illness, alcoholism, and other drug abuse.

² Chapter 55 provides protective services and protective placement, including emergency protective placement, for people with degenerative brain disorders, severe and persistent mental illness, developmental disabilities, and other similar incapacities that are likely to be permanent, who are incapable of caring for self and face a substantial risk of harm to self or others

³ DHS 34 establishes the standards and procedures for certification of county and multi-county emergency mental health service programs.

Dementia Crisis Innovation Grants

County crisis intervention systems have typically been oriented toward serving people in crisis due to mental health or substance use issues. However, just as someone with a mental illness or substance use disorder may sometimes become self-injurious or aggressive towards others, a small percentage of people with dementia may sometimes exhibit similar behaviors. Dementia may also lead to other behaviors that can be challenging to care providers. The appropriate response to challenging behaviors in an individual with dementia alone is likely to be different from the response needed for people who have mental illness or substance use disorders. Yet many county crisis intervention teams, even in counties with well-developed crisis response systems, do not have the training or resources needed to identify, evaluate, and manage people with dementia.

DHS released a [Dementia Care System Redesign Plan in 2014](#). A new [Wisconsin State Dementia Plan: 2019–2023](#) was created in 2018. Through these documents, DHS and its partners across the state have advocated a model for dementia-capable mobile crisis response that focuses on treating people with dementia who are in crisis in place, whenever possible. This approach maintains that stabilization services for an individual with dementia are ideally provided in his or her familiar living environment, whether that is a private home or a facility setting, by those who know the individual best. As much as possible, stabilization services should aim to avoid the disruption that comes with transferring the individual to an unfamiliar or unnecessarily restrictive setting.

There are not enough resources to develop separate crisis response systems for people with mental illness, developmental disabilities, substance use disorders, and dementia. Establishing separate systems also would not be efficient. For this reason, and recognizing that most county crisis intervention programs have limited training and capacity to identify, evaluate, and respond to people with dementia who exhibit violent, aggressive, or other challenging behaviors, the Department of Health Services funded competitive grants during 2016–2018 for counties or county consortia interested in improving the dementia capability of their crisis response systems.

The 18-month Dementia Crisis Innovation Grants required awardees to work collaboratively with a broad range of local stakeholders to review current crisis protocols and procedures, training needs, and resources available to support people with dementia experiencing crisis. These reviews aimed to highlight the strengths and gaps in grantees' abilities to respond effectively to a person with dementia in crisis and to help them develop improvement plans. In addition, awardees gathered previously uncollected data and generated ideas, tools, and information to share with others in order to further efforts to improve dementia-capable crisis response statewide.

There were two rounds of grant awards. The first grants, which ran from January 2016 through June 2017 and totaled nearly \$299,000, were awarded to six recipients:

- The Aging and Disability Resource Center of the North (ADRC-N), serving Ashland, Bayfield, Iron, Price, and Sawyer counties
- The Adult Protective Services Department of North Central Health Care (NCHC), serving Langlade, Lincoln, and Marathon counties
- Dodge County
- Kenosha County
- La Crosse County
- Milwaukee County

These grantees represented 12 counties and 27% of the state's population.

[Improving Dementia-Related Crisis Response: Results of Six Innovation Grants, P-02327](#), a report summarizing the activities of these grantees and the lessons learned, was issued in early 2018.

The second round of funding, which ran from June 2017 through December 2018, was open to new applicants as well as to applicants that received a grant in the first round of funding. Counties that received an award under Round One were expected to propose new activities to improve dementia crisis response beyond those carried out during the first round of funding. During Round Two, grants totaling more than \$421,000 were awarded to eight recipients. The Round Two grantees represented 10 counties and 43% of the state's population.

The Round Two awardees included five new recipients:

- Brown County
- Dane County
- A consortium of Oneida, Forest, Vilas counties;
- Polk County
- Waukesha County

These new grant recipients represented seven counties and 23% of the state's population. There were also three Round Two recipients that had also received a Round One grant:

- Dodge County
- La Crosse County
- Milwaukee County

These recipients represented 20% of the state's population.

Award Period	Number of Awards	Counties Represented	Percent of State Population
1. Round One (1/2016–6/2017)	6	12	27
2. Round Two (7/2017–12/2018)	8	10	43
a. New recipients	(5)	(7)	(23)
b. Received a Round 1 grant	(3)	(3)	(20)

Considered together, the 14 grants awarded through the two rounds of Dementia Crisis Innovation Grants funding went to agencies serving 19 different counties and 50% of the state’s population.

Further details regarding each Round Two grantee can be found in [Appendix 1](#).

Promising Practices Based on Innovation Grant Outcomes

Through the grants, counties created or enhanced collaborations among key stakeholders, gathered data about system needs, and implemented policies and practices to ensure a more coordinated, dementia-capable approach in supporting people with dementia in crisis.

The following sections, titled based off the grant’s goals and expectations, highlight some of the insights and promising practices arising from grantees’ collaborative efforts to improve dementia-related crisis response. Where examples from specific grantee projects are mentioned, they are intended to be illustrative, rather than comprehensive. Further details about grantees’ activities, achievements, and lessons learned are included in [Appendix 1](#).

1. Ensure leadership to oversee the activities of the project and build dementia capability.

All grantees emphasized the importance of having someone in a leadership or project management role early on to help organize, plan, and work with the broad coalition of partners. Without that role being filled, there were frequent delays in project activities, and responsibilities were reassigned to other agency employees. The grantees that were able to successfully engage a project manager seemed to make more immediate progress on their goals, without the delays experienced by others. Even those that were able to engage a project manager halfway through the grant period found they made more headway in their goals for the project with the person on board.

A couple of the grantees noted that counties with a designated dementia care specialist (DCS) at the local aging and disability resource center (ADRC) seemed to have an easier time with some tasks, such as building collaborative relationships among stakeholders and promoting community awareness about dementia. In fact, one grantee that did not have a designated project manager for the Innovation Grant and did not initially have a DCS at the ADRC found that when a DCS started at the local ADRC part-way through the grant period, the grant activities seemed to go more smoothly due to the focused attention that the DCS was able to bring to dementia-related efforts. This is consistent with the notion that having someone who can take the lead on building dementia capability may be critical to making progress in this area.

2. Engage a wide range of local stakeholders.

Many Wisconsin counties have coalitions focused on adult protective services, crisis response, and dementia-capable communities. These coalitions, which often engage in activities related to raising awareness, fundraising, supporting caregivers, and connecting people with local resources, may include a broad range of stakeholders, such as: crisis services, adult protective services, law enforcement, human services, mental health services, aging services, tribal agencies, corporation counsels, care facilities, home care providers, ADRCs, managed care organizations, hospitals, and other health care providers. In addition, every Wisconsin county is required to have an interdisciplinary team (I-team) whose primary focus is elder abuse and neglect.

The Round Two Crisis Innovation grants provided an opportunity for counties to integrate or expand local coalitions to focus specifically on dementia capability in crisis response. Grantees were expected to work collaboratively with a broad base of local stakeholders and to build communication, collaboration, and trust. Each grantee determined how best to use their local coalitions to achieve the goals of their grant. Most of the counties receiving Innovation Grants were able to expand existing coalitions, bringing new perspectives and resources to focus on crisis response for people with dementia. For example, the consortium of Forest, Oneida, and Vilas counties expanded their existing coalition to include caregivers and businesses. Milwaukee County, which had received a Round One grant, continued to strengthen their coalition during Round Two by adding additional partners, including nursing homes, community-based residential facilities, and adult family homes.

Several Round Two grantees noted that the improved communication and understanding among stakeholders that resulted from collaborating on grant-related activities was a major benefit of receiving the grant.

3. Conduct a review of the current policies, practices, and resources related to crises involving people with dementia to identify areas where improvements can be made.

Innovation Grant recipients were required to review current crisis protocols and procedures, training needs, and resources available to support people with dementia experiencing crisis. These reviews were intended to highlight the strengths and gaps in grantees' abilities to respond effectively to a person with dementia in crisis and to help them develop improvement plans. The review offered an opportunity to explore the capability and needs of specific stakeholders in the crisis response system and assess their ability and willingness to expand or improve their dementia capability. Those that received a grant in the first round had the opportunity to look at the resources developed during that first round and figure out ways to expand upon or improve those resources.

In several cases, these reviews led some grantees to recognize that the procedures for responding to a dementia-related crisis or the relationships among agencies with a role in the crisis response system were ill-defined, inconsistent, or duplicative. Several grantees also found that some partners misunderstood the roles, responsibilities, and limitations of other crisis system partners. Efforts to clarify procedures, roles and relationships took several forms. Some grantees established memoranda of understanding to formalize roles or relationships or established ongoing meetings or contacts where none previously occurred, in order to improve communications and the sharing of information among partners. Grantees sometimes created tangible products, such as flowcharts laying out the relationship among partners and the steps involved in responding to a crisis involving a person with dementia, to serve as aides to crisis teams and first responders. Brown County, for example, produced a new flowchart to lay out a step-by-step approach to assessing clients with dementia, in order to help address a lack of consistency between APS and the crisis center staff in the way these situations were handled. Dodge County reformatted an existing crisis flowchart to include dementia crisis response.

Grantees' examination of the dementia-related resources available to crisis workers, first responders, and formal and informal caregivers led to the development or adoption of a variety of dementia-related tools and resources. The following are just a few examples:

- Dane County created the "Helpful Information for First Responders" tool, building on a tool developed by the ADRC of Western Wisconsin.
- Dodge County created "Dementia Care Kits" to use during a crisis to help calm a person with dementia; introduced resource binders into local libraries for loan to people seeking information about dementia; and purchased billboard space in the county to display dementia-related resource and contact information.

- The Forest, Oneida, and Vilas consortium introduced the “Purple Tube Project” to ensure that first responders have access to critical information when they respond to a call at the home of a person with dementia.
- La Crosse County made support to family caregivers a focus of its Round Two grant, creating a peer support program for caregivers of people with dementia.

Examples of tools and resources developed by grantees can be found in Appendix 1.

4. Look for ways to improve all aspects of the crisis intervention continuum.

As noted, a small percentage of people with dementia may sometimes become self-injurious, aggressive, or violent towards others. Dementia may also lead to challenging behaviors such as wandering, entering others’ rooms uninvited, repetitive questioning, sexual inappropriateness, or refusal to accept care. Other people’s responses to such behavior can either alleviate or exacerbate these symptoms. Responding to challenging behaviors by removing a person with dementia from his or her living environment to an alternate setting can worsen confusion and agitation, cause unnecessary stress, and lead to negative health outcomes for the person. The goal, therefore, is to respond to behavioral symptoms in a way that causes the least possible disruption to the person.

In many counties, such an approach requires clarifying the roles and responsibilities for crisis response and stabilization among the various agencies involved, ensuring a common understanding among the agencies, and addressing the need for appropriate stabilization services as well as placement options for people with dementia who are in crisis and who need to be relocated.

Ensure a system-wide understanding of how to avoid or de-escalate dementia-related crises.

Since having to move to an unfamiliar environment is particularly stressful, and often traumatic, for people with dementia, all efforts should be made to avoid or minimize the need to move. Except in the case of people unknown to the system, planning for crisis should ideally begin before the crisis even occurs.

In part, this requires ensuring a system-wide understanding of what a “crisis” is and appropriate ways to avoid or de-escalate a crisis. One of the grantees, Waukesha County, noted that stakeholders may have different levels of experience or understanding when it comes to defining what constitutes a crisis. They also noted that while training for first responders and other professionals often includes information about recognizing and screening for dementia, such training may not include behavioral strategies for de-escalating a crisis when the person has dementia. Preventing a full-blown crisis, if possible, is always preferred.

Prioritize stabilization-in-place as the initial response to crisis for people with dementia, creating appropriate resources and supports.

While stabilization in place is the preferred approach for dealing with a dementia-related crisis, this cannot occur unless appropriate services and resources are available at the time and place when they are needed. Some grantee projects were able to make strides in creating stabilization-in-place options that worked well for individuals in crisis. The Forest, Oneida, and Vilas consortium developed a list of home health care providers willing to assist in the event of a crisis to help de-escalate the situation and help the individual stabilize in place. Dodge County created memoranda of understanding with providers to send staff to the home (or bring in extra staff to the facilities), in order to keep the individual in place, reducing the need for law enforcement to remove a person with dementia who is in crisis. La Crosse County developed contracts with home care providers in order to be able to pay for rapid response services, if necessary. They found it difficult, however, to find a provider with the staffing capability to quickly provide a worker to go to an individual's home.

Milwaukee County noted that insufficient funding remains a challenge to providing the necessary supports and resources for stabilization on a 24/7 basis. Grantees also acknowledged that additional and consistent follow-up after the crisis, both for individuals with dementia and those caring for them, needed further attention.

Identify residential facilities willing to accept people needing urgent placement who cannot be stabilized in place.

In some cases it may be necessary, at least temporarily, to relocate to a safe environment someone with dementia who is exhibiting challenging behaviors. In many areas of the state, however, long term care for people with extremely challenging behaviors is a missing link in the continuum of care for people with dementia. Many facilities either will not admit or will not retain people with dementia who exhibit challenging behaviors. A few county nursing homes, multi-county commissioned nursing homes, and the two state mental health institutes tend to be the placement of last resort. Even so, the need for this type of care typically outweighs the available capacity. Providers cite reimbursement rates and the risk of regulatory violations as barriers to serving this population. Wisconsin has no regulatory requirements that relate specifically to dementia care, and provider reimbursement rates do not reflect the additional cost of caring for this population.

Not having an adequate number of facilities willing to admit people in crisis can create difficulties for individuals and their families, and can challenge the resources of county agencies. Often, when crises happen, people with dementia will be relocated from their living environment to general hospitals or psychiatric facilities throughout the state, due to a lack of local facilities willing to admit people. The individual's destination may be far from his or her residence.

Grantees identified a number of factors that contribute to facilities' unwillingness to admit people with dementia who are in crisis. These factors include the need for medical clearance prior to admitting someone; the risk that people with aggressive behaviors may pose to the safety of residents and staff; associated regulatory pressures when individuals with challenging behaviors are moved to their facilities; and the need for contingency options should the placement not work out.

Some grantees were able to successfully address and navigate these issues to the satisfaction of facilities; others were not. Those who were able to expand the number of facilities willing to accept people in crisis did so by making improvements on a number of issues. For example, they refined protocols and incorporated them into their training modules. They created decision trees, rapid referral forms, and flow charts for crisis responders and others to use during crisis. In some counties, memoranda of understanding were developed for both the facilities that agreed to accept people in crisis and those that agreed to send staff to support people in their homes.

Conduct reviews following dementia-related crises to assess the outcome and inform program improvement efforts.

Several grantees reported establishing regular inter-agency reviews of situations involving dementia-related crises. In Dodge County, for example, weekly meetings were held by the crisis center, APS, and the ADRC. The consortium of Forest, Oneida, and Vilas counties reported that the three county Departments of Social Services held weekly meetings with the Human Service Center, which provides crisis services to the three counties. These reviews enabled agencies to assess the value of the protocols, tools, and resources available for dealing with dementia-related crises, and identify areas needing further attention and improvement. They also served to develop and reinforce habits of inter-agency communication and collaboration.

5. Evaluate and plan for local training needs in a way that is sustainable over time.

The grantees who received funding for the first time conducted a needs analysis to identify training gaps and solicit feedback from stakeholders. Grantees that had also received funding during the first round, already had a good sense of local training needs, and developed strategies to improve and expand training efforts with input and assistance from their coalition partners.

The grant required participants to track and report training activities in two separate categories: general training provided to a wide community audience, including families and caregivers; and specialized training targeted to crisis responders including APS, mental health crisis staff, law enforcement, emergency medical technicians (EMTs), and fire department personnel.

General training was often provided as part of community events meant to raise awareness of dementias. In most cases, nursing home and residential caregivers were trained at their facilities, while training for general audiences was done in the community at locations such as libraries or community centers. These trainings were very well received, and had excellent turnout, due in part to both marketing efforts and communities becoming more aware of the need for a better understanding of what dementia is and how it can affect people.

Grantees partnered with outside sources, such as Teepa Snow⁴ and other, more local stakeholders, to provide targeted training to a variety of audiences. For example, Brown County funded dementia-specific training for front-line professionals including the crisis center, a local nursing home, and law enforcement. Dane County funded on-line training for area agency on aging case managers who support people with dementia and their families. Additionally, La Crosse County provided training to the La Crosse City Fire Department, having provided similar training to other first responders during their Round One grant.

Grantees often provided targeted training using a train-the-trainer model for the sake of cost effectiveness, availability, and sustainability moving forward. Milwaukee County developed training videos depicting various situations of stress for both the individual with dementia and those caring for them. The goal in developing or expanding upon trainings was sustainability in a climate of high turnover and burnout.

Several grantees mentioned some challenges in working with certain target groups. Dementia training for crisis responders, law enforcement, fire departments, and emergency medical services (EMS) often involved accommodating the unique needs and schedules of those professions. In some cases, dementia training had to be incorporated into existing annual training activities, such as crisis intervention training (CIT). La Crosse County had planned to extend dementia training to residential facilities in the area, since direct care staff at these facilities often don't receive much training to work with people with dementia. However, they found the facility administrators less receptive to the training than expected for several reasons, including staffing shortages that made it difficult for workers to take the time for training. Dodge County reported some difficulty in providing dementia-related continuing education to medical professionals, due to the limited time those professionals have available and their potential concern about the negative impact to their relationship with a patient when giving a

⁴ Teepa Snow, owner and CEO of Positive Approach, LLC, is a leading trainer and consultant helping communities, agencies, organizations, professionals, families, and individuals develop the awareness, knowledge, and skills needed to better support and care for someone living with dementia.

dementia diagnosis. While not all grantees experienced the same types of obstacles, it suggests that targeted training efforts need to take into account the responsibilities, concerns, and pressures faced by the group that is the focus of the targeted training effort.

Regardless of the professional group receiving the targeted training, all grant counties reported that these trainings were well received and had a positive impact on response to crisis. One consistent theme arising from these grants, however, is that both targeted training and community awareness and education efforts need to be ongoing, or at least repeated periodically. Members of the general public may pay little attention to messages about dementia until it touches their own lives in some way, such as through the dementia diagnosis of a friend or family member, while high turnover among professionals and first responders means that there are continually new staff needing access to appropriate dementia-related training and resources.

Conclusion and Next Steps

This report presents insights useful for counties intending to improve their capacity for dementia-related crisis response, based on the outcomes of a second set of Dementia Crisis Innovation Grants (“Round Two” grants).

Having a county-based human services system, as Wisconsin does, means that it is not possible to develop or recommend a single approach to providing crisis services to someone with dementia. However, the experience of the Dementia Crisis Innovation grantees suggests that all counties can benefit from proactive, collaborative efforts to improve the dementia capability of the local crisis response system. Counties with well-developed systems for responding to mental health crises found that those systems can improve their ability to meet the somewhat different needs of people with dementia who experience a crisis. Counties with less well-developed crisis response systems were able to map the strengths and limitations of their systems and begin the process of developing the collaborative relationships and resources needed to improve their capacity to serve people with dementia in crisis. Thus the efforts of stakeholders across the state demonstrate that local and regional initiatives can be implemented or enhanced to develop system improvements and make current crisis systems more dementia-capable.

In February 2014, DHS released a [Dementia Care System Redesign Plan](#) to address gaps in the dementia care delivery infrastructure, including crisis services for people with dementia. The plan advocated a model for dementia-capable mobile crisis response that focused on treating people in place, when possible; clarifying roles and responsibilities for crisis response and stabilization; and addressing the need for appropriate placement options for people with dementia who are in crisis and who need to be relocated.

At a March 2018 stakeholder summit, DHS and a number of partners developed a new five-year plan to guide continued efforts to improve care and services for people with dementia and their

family caregivers. The [Wisconsin State Dementia Plan: 2019–2023](#) includes goals and strategies related to crisis response for people with dementia.

With the creation of a new Wisconsin State Dementia Plan, more collaborative efforts will be taking place across the state going forward. Thus, work accomplished through the Dementia Crisis Innovation Grants will continue through state plan implementation over the course of the next five years.

To stay informed on this plan and other DHS dementia news, please sign up for email updates on the DHS [Dementia-Capable Wisconsin](#) website.

Appendix 1

Round Two Dementia-Related Crisis Innovation Grantee Summaries

Brown County Health and Human Services Department

Description of Grant Activities

The focus of Brown County's grant was to enhance its ability to maintain individuals in their own homes or support them in a community setting for as long as possible. Brown County funded dementia-specific training for front-line professionals to improve the ability of local systems to support individuals in place and reduce unnecessary placements or moves. The grant was also used to develop on-call dementia crisis support services to reduce out-of-home placements and reduce caregiver stress by funding in-home assessments and interventions including respite, supervision, and assistive technology.

Achievements

Brown County provided dementia education to the crisis center, a local nursing home, and law enforcement. The grant enabled the local department of health and human services to form relationships with new community partners and allowed them to examine the county's crisis protocols and procedures when an individual with dementia is in crisis. Several benefits and insights resulted from this process. They discovered a lack of consistency between APS and the crisis center staff, resulting in individuals, hospitals, and law enforcement seeing different responses depending on what day or time a crisis occurred, and which agency was contacted for information or assistance. It also became clear that some partners lacked an understanding of the roles of others. To address these issues, the county produced a new flow chart to lay out a step-by-step approach to assessing clients with dementia. Education and collaborative efforts also contributed to improved consistency in response to a dementia-related crisis, regardless of when the crisis occurs or which agency is contacted. Data collection suggests that there has been an improvement in their ability to maintain individuals in their homes.

Lessons Learned

The county reported that the largest improvement resulting from the grant was having staff learn how to really look at the needs of clients with dementia and try to develop individualized plans to meet those needs, without resorting to placement. They did this in part by supplementing services and building on the individual's strengths. The review of the county's crisis protocols and procedures revealed that a high turnover rate at the crisis center poses an obstacle to maintaining consistency of practice across agencies. They are continuing to work on addressing the need for ongoing education of new staff.

Dane County Department of Human Services, Area Agency on Aging

Description of Grant Activities

Dane County Department of Health Services used the Dementia Crisis Innovation Grant to:

- Modify the model used by the City of Madison to address mental health crises for use with dementia-specific crises and implement this in the county's rural areas.
- Pilot the placement of a part-time crisis worker specializing in dementia into the crisis unit of Journey Mental Health Center (JMHC), to work collaboratively with law enforcement and first responders outside of Madison.
- Have the dementia crisis specialist develop a "Levels of Crisis" tool similar to the one used for mental health crises, to help define an appropriate response to a dementia-specific crisis.
- Develop a tool to help alert first responders to the needs of an individual experiencing a dementia-related crisis.
- Fund opportunities for rural case managers to complete dementia-related training.

Achievements

Building on a tool developed by the ADRC of Western Wisconsin, the local coalition created the "Helpful Information for First Responders" tool, which continues to be used by the ADRC of Dane County, Dane County Adult Protective Services, medical providers, first responders, the area agency on aging, and other entities that support people with dementia and their families. The grant was also able to fund 12 hours of online training for six rural case management providers using the Dementia Generalist and Dementia Specialist courses offered by the University of Wisconsin-Oshkosh. While the dementia crisis specialist was able to provide consultation and resources to the staff of Journey Mental Health Center, the county was not able to fully realize the placement of the dementia crisis specialist within JMHC as proposed.

Lessons Learned

In the past, there had been some dementia-related services provided to individuals in home and community-based waiver programs in Dane County, but this was limited to a small population. The grant helped the county recognize the need for a more widespread and inclusive approach to dementia-capable responses. The county encountered some difficulty in developing a "Levels of Crisis" tool to make decisions about the most appropriate level of care for someone with dementia experiencing a behavioral crisis. The attempt, however, enabled the system to clarify how the needs of people with dementia in crisis differ from those experiencing a mental health crisis, how the legal systems differ, and the types of resources needed to most effectively respond to a dementia-related crisis. The Dane County Board of Supervisors approved the addition of a new position, dementia crisis specialist, within Dane County Human Services in its 2019 budget. This position will continue the work started with the grant while also expanding its reach in other ways.

Dodge County Human Services and Health Department

Description of Grant Activities

Dodge County had a Round One Innovation Grant focused on educating existing county crisis staff and other stakeholders about dementia; creating and training new dementia crisis response teams for rapid response in a dementia-related crisis; and increasing community awareness and public education about dementia. The county's Round Two grant focused on reducing stigma; educating local medical professionals; and creating an environment that leads to earlier detection, diagnosis, and crisis intervention.

Achievements

Dodge County hired a designated project coordinator to facilitate collaboration, keep project activities on track, and continue the work of stabilization teams established under the first grant. Activities to further improve the crisis response system included:

- Reformatting their crisis flowchart to include dementia crisis response.
- Creating several memoranda of understanding with caregiver agencies willing to be first responders, especially during non-work hours.
- Establishing biweekly meetings with crisis staff, APS, and the ADRC for the purpose of reviewing cases handled through multiple departments to ensure that needs are being addressed.

Dodge County also gathered or developed various dementia-related tools and resources, including:

- Creating "Dementia Care Kits" to use during a dementia-related crisis to help calm the person with dementia.
- Assisting with the creation of the "Screening Algorithm for Adult Cognitive Impairment" tool.
- Introducing dementia-related resource binders into the local libraries, giving the libraries information they could loan out to those who wanted or needed it.
- Purchasing billboard space throughout the county to display resource information and a phone number for interested individuals to call to get more information.
- Starting a dementia-related webpage that will be sustained by several local agencies in the county after the end of the grant.

Lessons Learned

Prior to receiving the Innovation Grants, Dodge County's crisis system had no real guidance for how to handle dementia-related crises. The grant-funded training has helped to ensure that all agencies are on the same page and that their efforts are coordinated. Dodge County found it helpful to focus on internal processes and communication between the aging and disability resource center, adult protective services, and mental health crisis center. The weekly, collaborative meetings between these units now better serve the needs of Dodge County residents. One of the biggest achievements resulting from the grant was the relationships they

built with stakeholders. However, they found it challenging to work with medical professionals, whose schedules are such that they may have only limited time for education, and who may be concerned about the negative impact to relationships with a patient when giving a dementia diagnosis.

Forest, Oneida, and Vilas Counties

Description of Grant Activities

The social service departments of Oneida, Vilas, and Forest counties have worked collaboratively with a number of coalition members for over 10 years on issues related to the Wis. Stat. chs. 51 and 55 systems. The Human Service Center (HSC) provides Chapter 51 services in the tri-county region. The Crisis Innovation grant enabled these agencies to work toward creating a dementia-capable crisis prevention and response system focused on stabilization in place. Long-term goals were to reduce the number of detentions and protective placements; reduce the level of trauma experienced by residents requiring intervention; seek preventive measures to detentions; understand the role and limitations of each agency; and build collaborative relationships.

Achievements

Hiring a project manager facilitated the projects and activities conducted under the grant. With the support of the grant, coalition members:

- Broadened their membership to include caregivers and businesses.
- Conducted an inventory and analysis of local dementia resources, a task complicated by the fact that each of the three counties has different services and different gaps in services.
- Developed a stabilization-in-place resource utilizing local home care providers.
- Established a list of home health care providers willing to assist in the event of a crisis to stabilize in place, developing a memorandum of understanding to clarify those relationships.
- Provided training to professionals and caregivers as a way to prevent crisis, and developed strategies for sustaining those training efforts. Coalition members hoped this training would result in earlier and timelier referrals and reduce the likelihood of situations rising to a crisis level.
- Implemented the Purple Tube Project in December 2018, to ensure that first responders have access to critical information when they respond to a call to the home of a person with dementia.

There has been a significant increase in communication between all of the agencies and improved understanding of the roles and capabilities of each agency. There is now a weekly conference call between the tri-county departments of social services and the HSC for the purpose of crisis debriefing.

Lessons Learned

One of the most valuable things to occur as a result of the grant was meeting with providers face-to-face to establish a connection and to communicate with each other. This allowed coalition members to learn what each agency or provider was capable of doing, as well as hearing frustrations and better understanding their needs. They learned that the large stakeholder group was great for disseminating information, but to complete tasks or projects, it was important to establish subgroups to carry out specific tasks.

La Crosse County Human Services

Description of Grant Activities

La Crosse County was a recipient of a Round One Innovation Grant, which included multiple components, including analyzing existing community resources, strengthening coalitions and partnerships, assessing the current crisis response system, developing both a continuum of crisis response options and a community training plan, implementing Music and Memory in home settings, and providing dementia-related training to law enforcement and first responders. The Round One Innovation Grant enabled La Crosse County to identify areas needing additional efforts, one of which was the isolation and uncertainty facing the family caregivers of someone with dementia. The Round 2 grant enabled the county to address this issue, as well as continuing their efforts to increase education and awareness about dementia in the La Crosse region.

Achievements

The new grant allowed La Crosse County to collaborate with Causeway Interfaith Caregivers, Inc. and the Alzheimer's Association to meet the needs of family caregivers in the community by developing and implementing a peer support program. The county also provided training to memory care facility staff to help them learn new strategies for working effectively with people with dementia in a crisis, thereby reducing the need for emergency protective placements. Dementia-related training was also provided to the La Crosse City Fire Department, which had not received the training along with other first responders during the period of the first grant. Finally, the new grant allowed further development of processes for rapid response to needs for support after a crisis.

Lessons Learned

During the first grant cycle, La Crosse County utilized a project manager to oversee the projects, but they did not have someone in this capacity during the second grant, which caused some challenges. However, in September 2018, during the last months of the Round Two grant period, a dementia care specialist started at the ADRC of La Crosse County. They found that in the absence of a project manager, having a dedicated dementia care specialist was very helpful in building awareness and further developing the dementia coalition and other dementia-related initiatives. La Crosse County had planned to extend dementia training to residential facilities in the area in order to increase their capability in crisis planning, response, and stabilization for people with dementia. For a variety of reasons, however, including staffing shortages making it

difficult for direct care staff to take time for training, there was less buy-in from the facility administrators than the county had hoped for. Still, the residential facility staff that did undergo training were very responsive and found the training helpful.

Milwaukee County Department on Aging

Description of Grant Activities

As a Round One Innovation Grant recipient, Milwaukee County was able to create a process for crisis stabilization for people with dementia. This included establishing partner teams, behavioral supports, prevention efforts, and a crisis response plan with the goal of “stabilization in place.” They also focused on expanding the local dementia coalition. The Round Two Innovation grant was used to provide further improvement to the crisis system in Milwaukee, specifically addressing ongoing barriers. In addition, feedback received during the first grant indicated that family caregivers and residential care providers wanted more training and resources in a format that could be used in multiple ways without a large time commitment. The second grant enabled the county to develop a series of six brief 2-5 minute videos, with an accompanying training guide, for use in residential facilities or in private homes.

Achievements

With the support of the Round Two Innovation grant, Milwaukee County was able to:

- Add additional coalition partners that included nursing homes, community-based residential facilities, and adult family homes willing to work with hospital staff to accept people with dementia who also have challenging behaviors, and cannot return to their previous living environments.
- Add two more home care and supportive care agencies to provide support and stabilization services, respite, and care for people with dementia in their homes.
- Film a short video with first responders that has been widely accepted and will provide needed training on responding to people with dementia in crisis by emergency medical services, first responders, and police officers.
- Strengthen the relationship with the Milwaukee County Behavioral Health Crisis Team, and educate them about dementia.
- Create six short videos that portray various challenging scenarios from the point of view of a person living with dementia, as well as an accompanying facilitator guide. The videos, which focus on understanding dementia, identifying what makes a crisis, demonstrating proper techniques for de-escalation, and avoiding or minimizing the crisis, are available in a digital format such as YouTube and hard copy on a flash drive, and are available for statewide distribution and use.

Lessons Learned

One of the challenges that coalitions often face is that each partner agency has their own priorities and objectives. Milwaukee County reported that one of the greatest successes of this project was that it brought together major stakeholders to commit to a common goal and

process. The Innovation Grant project offered opportunities to provide cross-training to crisis teams in order to equip them with the knowledge and skills needed to respond to people with dementia. Insufficient funding is the main barrier to developing 24/7 mobile response capacity for people with dementia in crisis. However, the Emergency Protective Placement Coalition remains committed to working toward a 24/7 crisis response capacity for people with dementia.

Polk County Behavioral Health Department

Description of Grant Activities

The Polk County Emergency Services Collaborative (PCEC) was formed in 2015 to provide a coordinated response to mental health emergencies. With the Dementia Crisis Innovation Grant, Polk County initially proposed forming a task force under the PCEC to improve the dementia capability of the county crisis response system. However, upon learning that the ADRC of Northwest Wisconsin was moving towards development of a dementia coalition, the Behavioral Health Department decided to join with this initiative instead, in order to maximize the time of key stakeholders.

Achievements

Polk County used the Innovation Grant to assess current strategies related to dementia crisis interventions, as well as the training and support needs of local crisis responders and care providers. Three community trainings were conducted, and further training will be carried out in collaboration with the ADRC and the newly formed dementia coalition. They developed a localized resource guide used by emergency services workers; adopted a crisis decision tree established by Bayfield County; and increased the use of the File of Life in the community. In a related effort, the ADRC added a dementia resource section to their web page. A goal of developing a three-year plan to provide dementia training to first responders, APS, and crisis workers in Polk County was not fully realized, but they continue to collaborate with the ADRC, dementia coalition, and APS in order to continue the training needed to increase the dementia capability of the county's crisis responders.

Lessons Learned

Through meetings and collaboration with key stakeholders and staff from the ADRC, there has been improved communication among the stakeholders, leading to an increased awareness of everyone's roles and responsibilities. However, it was sometimes difficult to find the time for these important conversations on top of everyone's other duties. Polk County reported that an area they struggled with was increasing care in the community to stabilize in place, due to a critical work force shortage in local care facilities. This issue has been a growing area of concern. Other barriers were the lack of emergency protective placement facilities and services to allow stabilization in place. The lack of funding for skilled nursing homes to train and retain staff to address the challenges of an emergency protective placement make it difficult to stabilize individuals in nursing homes, resulting in emergency detentions through Chapter 51.

Waukesha County Department of Health and Human Services, Aging and Disability Resource Center

Description of Grant Activities

Waukesha County received funding for a dementia care specialist in July of 2014, which helped to develop the partnerships, resources, and training needed to make the county more dementia-capable. The Innovation Grant was used to further improve the dementia capacity of their existing crisis response system. The goals of the project were to:

- Develop a steering committee that is comprised of members from numerous stakeholders and agencies throughout the county.
- Examine the formal and informal responses to individuals with dementia who exhibit challenging behaviors in Waukesha County.
- Examine the resources available for these individuals and their caregiver support system.
- Recommend improvements to these processes and resources.
- Build a strong coalition of stakeholders that will continue working to improve care for individuals with dementia exhibiting challenging behavior and identify ways to support their caregivers.

Achievements

Waukesha County reviewed their existing system to ensure a wide range of stakeholder representation and engagement by both professional and community individuals and organizations. The county conducted a comprehensive inventory and analysis of local dementia care resources, provider response plans and staff training, and identified gaps and needs. They also developed a crisis response training for community-based providers.

Lessons Learned

Several critical insights resulted from the work of the steering committee. First, they realized that individuals with dementia in crisis are often treated as suffering from a mental health crisis. Although sometimes individuals do suffer from both, there is a distinct difference in how to handle their crisis. First responders, law enforcement, and crisis workers often receive education on how to handle a mental health crisis, but are less likely to receive training on how to handle an individual with dementia who exhibits challenging behaviors. This can lead to an escalation in behavior. The steering committee also found that the definition of what a "crisis" is varied significantly among stakeholders. Finally, they determined that training staff about dementia did not always include behavioral crisis training. Many facilities and programs train staff about the causes and symptoms of dementia, but do not provide opportunities for caregivers and other stakeholders to learn how to respond appropriately in a way that de-escalates a crisis. These findings were important as the steering committee recognized a significant challenge facing the community was developing a shared understanding of what a crisis is, as well as identifying appropriate training for caregivers.