# WISCONSIN LEGISLATIVE COUNCIL

# LEGAL INTERVENTIONS FOR PERSONS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

Room 411 South
State Capitol

September 12, 2012
10:00 a.m. – 4:10 p.m.

[The following is a summary of the September 12, 2012 meeting of the Special Committee on Legal Interventions for Persons With Alzheimer's Disease and Related Dementias. The file copy of this summary has appended to it a copy of each document prepared for or submitted to the committee during the meeting. A digital recording of the meeting is available on our Web site at **http://www.legis.state.wi.us/lc.**]

## Call to Order and Roll Call

Chair Knodl called the committee to order. The roll was called and staff noted that a quorum was present.

| | |
|---|---|
| COMMITTEE MEMBERS PRESENT: | Rep. Dan Knodl, Chair; Rep. Penny Bernard Schaber, Vice Chair; Sens. Neal Kedzie and Robert Wirch; and Public Members Suzanne Bottum-Jones, Kathi Cauley, William Hanrahan, Tom Hlavacek, Gina Koeppl, Robert Lightfoot, Rob Mueller, Wanda Plachecki, Brian Purtell, Tom Reed, Kenneth Robbins, and Chrystal Rosso. |
| COUNCIL STAFF PRESENT: | Brian Larson, Staff Attorney and Mary Matthias, Senior Staff Attorney. |
| APPEARANCES: | Charlie Morgan, Program Supervisor and Grant Cummings, Fiscal Analyst, Legislative Fiscal Bureau; Representatives from the Department of Health Services: Otis Woods, Division Administrator, and Pat Benish, Program Specialist, Division of Quality Assurance; Dr. Molli Rolli, Medical Director, Mendota Mental Health Institute; and Alice Page, JD, MPH, Adult Protective Services and Systems Developer, Bureau of Aging and Disability Resources, Division of Long Term Care. |

## Approval of the Minutes From the July 31, 2012 Meeting of the Special Committee

*Vice Chair Bernard Shaber moved, seconded by Mr. Hlavacek, to approve the minutes of the July 31, 2012 meeting. The motion passed on a unanimous voice vote.*

## Presentations by Invited Speakers

Chair Knodl welcomed the members of the committee. He explained that after the presentations by the invited speakers, the committee would begin discussions to identify the members' priorities and direct staff to begin work on draft legislation on those issues.

***Charlie Morgan, Program Supervisor and Grant Cummings, Fiscal Analyst, Legislative Fiscal Bureau***

Grant Cummings presented the information contained in the memorandum to Representative Dan Knodl, Chair, from Grant Cummings, Fiscal Analyst, Legislative Fiscal Bureau, *Use of Chapter 51 and 55 Procedures to Address Challenging Behaviors of Individuals With Alzheimer's Disease and Dementia* (July 24, 2012).

Mr. Cummings also provided a handout containing the following information: *Individuals with Dementia Admitted to Public or Private Inpatient Facilities, Calendar Year 2011*, and *Mendota Mental Health Institute Admissions of Civil Patients with Primary Diagnosis of Dementia, by County*. He explained that the 112 individuals admitted under ch. 51 in 2011 represents only individuals who were already in the county system, social services, or mental health in some capacity. The average length of stay of these individuals at Mendota was 23 days.

Mr. Cummings stated that although the statutes require all counties to establish an intake facility for ch. 55 placements, not all counties have done so. Mr. Cummings described multi-county commissions that have been established to create specialized psychiatric treatment units in nursing homes which are shared by all participating counties.

Mr. Cummings said that in the course of gathering information for the memorandum, various individuals stated that if an individual is placed in a psychiatric hospital or unit under ch. 51, it may be difficult to find a long-term care facility that is willing to accept the person as a resident when they are ready for discharge from the psychiatric facility. It was also stated that if a person's initial placement is a psychiatric facility, the individual is subjected to the stress of moving to a new residential setting upon completion of treatment. Concerns were also expressed that if pressure is placed on nursing homes to keep residents in-house even when they exhibit difficult behaviors, nursing homes may be reluctant to accept individuals with dementia for initial placement even if they do not have a history of difficult behavior.

***Otis Woods, Division Administrator, and Pat Benish, Program Specialist, Division of Quality Assurance (DQA), Department of Health Services (DHS)***

Mr. Woods provided a handout of his testimony to the committee. He described the duties of and activities undertaken by the Division of Quality Assurance in regulating and licensing nursing homes and assisted-living facilities. He explained that DQA inspects nursing homes to assess for

compliance with state regulations and also assesses for compliance with federal regulations on behalf of the federal Department of Health and Human Services Centers for Medicare and Medicaid Services (CMS). He discussed the regulations that require a facility to remove a resident if their behavior becomes injurious to themselves or others, and the work DQA has done to promote "person-centered care" in nursing homes. He said much of this work has been done in collaboration with advocacy groups and representatives of long-term care trade associations. In response to questions, he explained that Wisconsin does not have any special regulations for facilities that serve individuals with dementia.

When asked about citations related to challenging behaviors by residents with dementia, Mr. Woods said that DQA staff realizes that these behaviors can be unpredictable, but that it is expected that when a resident initially demonstrates this type of behavior, the facility will take appropriate steps such as making changes to the individual's plan of care so that the facility can provide a coordinated response when the behavior recurs. He said that facilities that are cited often demonstrate a failure to respond to resident's behavior, which exacerbates the situation. He said DQA is in the process of developing training to be provided to DQA staff in how to evaluate the appropriateness of a facility's response to an individual with Alzheimer's Disease. In response to another question, Mr. Woods stated that he would provide the committee with information regarding appeals of involuntary transfer or discharge from a nursing home in situations in which a resident poses a danger to other residents. Mr. Woods explained that psychiatric facilities are licensed under ch. DHS 124, Wis. Adm. Code and applicable federal regulations which differ depending on the type of care provided at the facility.

In response to a question, Mr. Woods stated that although CMS is not, to the best of his knowledge, currently developing special standards for Alzheimer's facilities, CMS has undertaken some special initiatives for care of people with dementia. He said that DQA recently made changes to the regulations governing assisted living facilities to make them specific to the types of clients served and suggested this could be a model for nursing home regulation. Mr. Woods agreed that assisted living may be a preferable setting for individuals with acute care needs related to dementia and noted that there have been successes in using smaller environments including CBRFs to care for individuals with acute needs.

When asked whether additional funding would be provided for dementia facilities if a separate certification process were established, Mr. Woods said he would not make that determination. He said that separate standards for dementia facilities have been developed in other states. In response to a question, Mr. Woods said he is not aware if there is a correlation between the amount of staff training or staff turnover in a facility and the number of citations received by a facility. He said he would check to see if DQA maintains any data that might be used to evaluate this issue.

***Dr. Molli Rolli, Medical Director, Mendota Mental Health Institute (MMHI)***

Dr. Rolli provided a handout of her testimony to the committee. She described the services provided to patients with dementia at the specialized geriatric unit at MMHI. She said that the high staffing levels and care provided by occupational and physical therapy staff are crucial to success with this population. She said MMHI is not a long-term care facility but is intended for short-term stays to stabilize people and get them back to their normal residential setting. Dr. Rolli said the average length of stay for dementia patients at MMHI is about 33 days. She discussed several rare cases in which dementia residents remain at MMHI for long periods of time.

Dr. Rolli estimated that about 1/3 of the dementia patients at MMHI came there directly from their own home, while about 2/3 were residing in a facility before they were admitted to MMHI. She

said it is unlikely that many individuals admitted to MMHI are able to return to their own home after they leave MMHI but rather a supported living environment is found for them. She said that since MMHI is very expensive, counties don't typically send individuals to MMHI unless they truly need the high level of care that MMHI provides.

In response to a question regarding the "dual diagnosis" terminology used in the *Helen E.F.* case, Dr. Rolli stated that the determination of a person's psychiatric diagnosis can sometimes get down to semantics. For example, if a person with dementia has hallucinations, some psychiatrists might diagnose the person with separately occurring psychosis while others would consider the hallucinations to be a symptom of dementia.

Dr. Rolli explained that individuals with dementia typically come to MMHI via a ch. 51 emergency detention which is converted to a ch. 55 proceeding at the probable cause hearing. Once this conversion takes place, MMHI may hold the individual for up to 30 days, which is sufficient time to stabilize most individuals. Occasionally more time for treatment is needed, but the *Helen E.F.* case requires the person to be transferred out of the psychiatric facility after 30 days.

Dr. Rolli said a high level of expertise is needed to determine whether an elderly individual demonstrating challenging behaviors has dementia, another psychiatric diagnosis, or both. She said this diagnosis cannot be made "on the spot" in an emergency situation, particularly when the individual is unknown to the county mental health system. She said it would be preferable to have a process under which elderly individuals can come to MMHI by means other than the current process which involves the police. She said that in other states, law enforcement is not as involved in the emergency detention process, but rather guardians and clinicians have more control. She suggested the committee develop a procedure that would enable elderly patients with dementia to get treatment without going through what feels like an arrest.

In response to a question, Dr. Rolli said that some individuals with dementia need to be treated with psychotropic medication. She also said that better access to mental health assessment and treatment could, in some instances, help avoid the need to transfer individuals with dementia to MMHI.

Dr. Rolli suggested that the 30-day limit on inpatient psychiatric care in ch. 55 be increased, with a provision for an extension of the initial treatment period after judicial review. She said that an individual's need for treatment changes over time so reviewing a treatment order more frequently than a ch. 55 placement order would be appropriate.

***Alice Page, JD, MPH, Adult Protective Services and Systems Developer, Bureau of Aging and Disability Resources, Division of Long Term Care***

Ms. Page provided a handout of her testimony to the committee. She presented information on the demographics of the population with Alzheimer's Disease and dementia. She described the activities of the Division of Long-Term Care relevant to individuals with dementia, including the adult protective services system and the adults-at-risk abuse response and reporting system. She explained the role of counties in these systems and how the systems interact. She explained the use of Interdisciplinary teams (I-teams) in some counties that plan community responses to problems that put adults at risk of abuse or neglect.

Ms. Page also described the funding and operations of Aging and Disability Resource Centers (ADRCs), which can provide support to family members and caregivers who interact with individuals

with dementia and challenging behaviors. She said a new dementia care specialist position is being created at several ADRCs. She described the types of behaviors exhibited by individuals with dementia and the causes of these behaviors. She discussed various approaches to addressing these behaviors, including person-centered care models, and discussed the risks of psychotropic medications with this population.

Ms. Page described several programs administered by the Division of Long-Term Care that serve people with dementia in the community. She said the goal of DHS is to provide supports and interventions that help avoid or postpone the need for costly long-term care.

In response to a question, Ms. Page stated that counties are interpreting the *Helen E.F.* case in different ways, and there are differing levels of training on dementia-related issues among law enforcement agencies throughout the state. She said that the I-team approach would be a good model for providing flexibility while ensuring appropriate community responses to the needs of individuals with dementia, particularly in crisis situations.

## Discussion of Committee Options Paper

***Memo No. 1, Summary of Recommendations Made to the Special Committee at the July 31, 2012 Meeting***

Chair Knodl asked committee members to share their thoughts on the recommendations set forth in Memo No. 1 and identify the issues they feel should be given highest priority. Dr. Robbins said that he is concerned that due to confusion brought about by the *Helen E.F.* case, law enforcement is reluctant to detain individuals with dementia even when they pose a danger to themselves or others. He also discussed the approach taken by the geropsychiatric unit at Stoughton Hospital in dealing with dementia patients and stressed that psychotropic medications are not used indiscriminately. He said it would be very helpful if facilities that send residents to psychiatric units would provide more data about the persons behavior to help the unit determine the precipitants of the behavior.

Ms. Bottum-Jones discussed the importance of training and knowledge for both facility staff and family members. She said that the goal of treating people "in-place" is good but that access to medical professionals in many residential settings must be improved to make this option feasible.

Ms. Koeppl discussed the importance of access to psychiatric and medical care in crisis situations and the negative effects of the current ch. 51 procedures on the elderly in her community, who must endure detention by law enforcement, long waits in emergency rooms and possibly a four-hour ride to MMHI under sedation. She said the difficulties of finding placements for people after short-term psychiatric treatment is completed often leads to the person remaining in the crisis setting much longer than necessary. She said there is a need for more specialized CBRFs to serve individuals with dementia.

Mr. Lightfoot said long-term care providers have had their hands tied by the *Helen E.F.* decision. He said providers need a tool to address needs of residents who cannot safely be cared for in-house. He expressed concern about requiring more training for providers, saying that training requirements are already formidable.

Mr. Hlavacek stated that he supports establishing a special procedure in ch. 55 for the provision of psychiatric care for individuals with dementia and suggested that ch. 51 be used only for individuals with a mental illness that is clearly separate from their dementia. He stated that individuals with

dementia receiving psychiatric treatment should be kept separate from other psychiatric patients and that these people should never be held at the Milwaukee Mental Health Center. He supports the goal of treatment in place, the use of mobile crisis units, and the development of alternative facilities for the provision of psychiatric care for individuals with dementia. He said care plans for residents with dementia developed by long-term care facilities should focus specifically on dementia issues, including use of medical evaluation and behavior-based strategies to address challenging behaviors.

Ms. Rosso emphasized the need for evaluation and monitoring of psychiatric needs of individuals with dementia and the need for short-term placements for psychiatric treatment with the goal of returning a resident to their original setting as quickly as possible. Ms. Plachecki stated that requiring more regulation, training, and sanctions would be counterproductive. She said the goal must be to provide the right treatment at the right time, which requires a quick and flexible procedure allowing for a short term stay in a psychiatric facility when needed.

Mr. Mueller stated that there are over 1,200 emergency detentions per year in Waukesha County. He suggested that the committee develop proposals to expand opportunities for advance planning, such as allowing a health care agent to consent to a short-term psychiatric placement for a principal. He said that regulations should not require more training, but rather focused training of the type provided at North Central Health Care. He said changes should be made to enhance the ability of doctors to treat patients in-place by allowing agents and guardians to consent to the administration of medications when needed. He stressed the importance of treating the elderly with dignity and providing treatment in a manner that does not jeopardize their ability to find a residential placement after treatment is completed.

Mr. Reed agreed with previous speakers that elderly individuals with dementia who need psychiatric care are very different from other mental health patients. He said the statutes need to be revised to take this difference into account. He agreed that a procedure for obtaining psychiatric treatment should be created within ch. 55 and law enforcement needs to be given guidance on any new procedures established. He supports treating in-place and stressed that transfer trauma needs to be avoided whenever possible. He discussed the need to develop less costly settings to care for this population and the need to avoid creating new regulations that could drive up the costs of care.

Mr. Purtell discussed several situations in which the involuntary discharge of a resident with dangerous behavior was appealed, resulting in high costs to the facility. He agreed with other speakers about the need to develop a system within ch. 55 to take timely action to provide psychiatric care to individuals with dementia. He said ch. 55 is preferable to ch. 51 because it does not have the same stigma attached to it. He suggested that for individuals who were not residing in a regulated facility prior to the need for psychiatric care, consent to psychiatric treatment and admission might be more appropriately provided under ch. 50. He also agreed that changes should be made to enhance the ability of health care agents to provide consent to psychiatric care.

Ms. Cauley stressed the need for developing an option for detention that does not involve the use of handcuffs during transport, although she expressed concerns over requiring mobile crisis teams to provide all transportation. She stated that if additional training and care planning are mandated, additional funding should be provided to facilities to cover the additional costs they will incur.

Vice Chair Bernard Shaber said she would like more input from law enforcement regarding their role in the emergency detention process. She said it will be important for counties and law enforcement personnel to reach consensus on proper procedures to be followed under the *Helen E.F.* case until

legislation is enacted to modify and clarify emergency detention procedures. Chair Knodl agreed and asked staff to arrange for representatives of law enforcement to appear at the Committee's next meeting.

Chair Knodl stated his concern that any proposals developed by the committee be appropriate and feasible for both urban and rural areas of the state. After further discussion with staff and committee members, he directed staff to prepare bill drafts for the committee to review at its next meeting, addressing the authority of health care agents and guardians to consent to psychiatric treatment and admission for inpatient psychiatric treatment for a principal and the provision of short-term psychiatric treatment for individuals with dementia within ch. 55, Stats. Staff explained that they will review the committee discussion and prepare several drafts based on that discussion which will present various options for the committee's consideration. Staff will also provide information regarding several questions raised regarding training of nursing home staff and the impact of federal regulations on nursing home attempts to treat in-place.

## Other Business

Mr. Hlavacek told the committee that the Alzheimer's Association Task Force on Challenging Behaviors will present its final report at an all-day conference on November 1. Details will be e-mailed to committee members when they are available.

Chair Knodl reminded members that the next meeting of the committee will be held on October 18th, in the State Capitol.

## Adjournment

The meeting was adjourned at 4:10 p.m.

MM:ty