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**Wisconsin Legislative Council Special Committee on Legal Interventions
For Persons with Alzheimer's Disease and Related Dementias**

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Good morning. Mr. Chairman and members of the committee, I am Alice Page, Adult Protective Services and Systems Developer for the Department of Health Services in the Division of Long Term Care, Bureau of Aging and Disability Resources. I am here this morning on behalf of the Division of Long Term Care, which is responsible for a variety of programs that provide services and supports to adults and children, in large part directed at keeping individuals in their homes and communities.

One of the populations served by the Division includes people with Alzheimer's disease and related dementias. Estimates from 2010 suggest that 109,000 Wisconsin residents have Alzheimer's disease and are living in the community. According to the Alzheimer's Association, one in seven people with dementia living in the community live alone and up to half of those who live alone do not have anyone identified as a caregiver. Those who live alone are exposed to higher risks, such as inadequate self-care, malnutrition, untreated medical conditions, falls, wandering from home unattended, and accidental deaths. They may not have been diagnosed and may be unknown to the long term care community until a crisis occurs. Another 16,000 Wisconsin residents with Alzheimer's disease live in skilled nursing facilities.

The number of persons with Alzheimer's disease is expected to increase by 68 percent to 210,000 by 2035 due primarily to longer life expectancy and the aging of the Baby Boomers. The Alzheimer's Association estimates that one in eight Baby Boomers will develop Alzheimer's disease, and if they do not develop the disease, they will be caring for someone who has. In Wisconsin, the proportion of the population that is 65 and over will be disproportionately greater in northern rural counties where almost one third of the population will be age 65 or older by 2035.

The aging of Wisconsin's population will strain both acute and long term care resources, especially Medicaid. Typically by age 80, only four percent of Americans will have support needs that meet a nursing home level of care compared to 75 percent of people with Alzheimer's disease. In Wisconsin, 54 percent of skilled nursing facility residents have a dementia diagnosis. Fifty-nine percent of skilled nursing facility residents are age 85 or older, and 52 percent have been in a facility for more than two years.

It is difficult to obtain a clear picture of the cost of serving people with dementia. As I mentioned previously, about 16,000 individuals in skilled nursing facilities have a diagnosis of Alzheimer's disease or another dementia. We know from the Minimum Data

Set, which is collected in nursing homes that receive Medicaid reimbursement, that 48 percent of these residents had part or all of their care paid by Medicare in 2008, and 45 percent had part or all of their care paid by Medicaid. Some of these residents are recipients of both Medicare and Medicaid. Traditionally, states have not had access to Medicare payment information, but that is changing. Costs of dementia care in various programs are not readily available as payment mechanisms do not identify diagnosis.

A much larger number of people with dementia live in community settings, including private homes and assisted living facilities. However, the 2010 estimate of 109,000 residents does not specify the type of residence, or identify how many individuals receive paid or unpaid care.

The Division of Long Term Care oversees program and policy development for adult protective services, which operates under Chapter 55 along with the adults-at-risk abuse response and reporting system. Closely linked to Chapter 55 are Chapter 46, which governs the elder adults-at-risk abuse response and reporting system; and Chapter 54, which governs guardianships. The laws provide mechanisms for receiving and responding to reports of abuse or neglect; for organizing, planning, and delivering services from public and private agencies; for delivering voluntary services to those who need them and request or accept them; and for determining whether protective services or protective placement can be provided without consent of the individual at risk, either with consent of an agent vested with decision-making authority under a power of attorney or a guardian, or by court order.

Primary responsibility for service planning and delivery in all of the areas I just mentioned rests at the county level. Each county is required to identify a lead elder-adults-at-risk agency for adults age 60 and over and an adults-at-risk agency for adults ages 18-59 to take primary responsibility for receiving and responding to allegations of abuse, neglect, and exploitation. Most counties combine these functions in the same agency. Each county is also required to designate an adult protective services agency responsible for providing protective services and protective placement to all adults-at-risk regardless of age. A distinctive feature of adult protective services is the use of legal interventions when required. These three county functions are often referred to as the county adult protective services unit.

An adult-at-risk includes an adult of any age who has a physical or mental condition that substantially impairs his or her ability to care for his or her needs and who has experienced or is at risk of abuse, neglect, or exploitation. In contrast, the population served by the adult protective services system is defined by membership in one of four disability groups, including degenerative brain disorder, and a requirement that the person is unable to meet his or her needs for care.

The response and reporting system for adults-at-risk feeds into adult protective services by performing functions such as initial response, including investigation, outreach, identification of individuals in need of services, and identification of service needs. There are a variety of mechanisms by which protective services may be provided. Protective

services include any service that helps keep the adult-at-risk safe from abuse, neglect, or exploitation or prevents harm to the adult-at-risk or to others. Protective placements are considered to be a protective service. Adult protective services works closely with family members, managed care organizations, medical personnel, community programs, facilities, financial institutions, law enforcement, and the courts.

The Division of Long Term Care provides some funding to counties for prevention of elder abuse. Each county that accepts this funding must organize and operate an Interdisciplinary Team, or I-Team, for the purpose of providing a multi-disciplinary approach to plan and discuss community responses to problems that put adults at risk of abuse and neglect. Members of the I-Team represent agencies or disciplines in the public and private sectors including social services, aging services, law enforcement, emergency department staff and first responders, providers of domestic violence services, bankers, and even humane societies. I-Team members bring together a variety of skills, knowledge, ideas, training, and backgrounds to discuss and consult on specific cases and systems issues. By ensuring continuous exchange of information among member agencies and organizations, cooperation and coordination is enhanced across the community. The outcome is a broader range of strategies, solutions, and perspectives for addressing complex situations involving adults-at-risk. Some I-Teams have developed protocols for how communities will respond to challenging behaviors exhibited by persons with dementia. If key community resources have the same perspective on dementia, then responses can be more effective.

The Division funds programs operated by county government, usually through the Aging Network or through Aging and Disability Resource Centers. These local agencies support family members, caregivers, and other stakeholders who regularly interact with people with dementia to understand and respond appropriately to what are commonly referred to as challenging behaviors. The most common behaviors exhibited by individuals with dementia include wandering, pacing, repetitive calling out or questioning, screaming, sundowning (where an individual feels the strong urge to leave where they are and go 'home,' generally in the late afternoon), day and night schedule reversal, and refusal to accept personal cares. Persons with dementia may strike out or exhibit other aggressive behaviors while a caregiver attempts to address these behaviors to provide personal care.

Challenging behaviors are exhibited by many individuals with dementia from time-to-time during the course of the disease. Service providers and physicians recognize that these behaviors are common and that they should be expected and planned for. Researchers and practitioners indicate that these challenging behaviors are often a way for persons with dementia to communicate when, because of their diminished capacities, they are no longer able to verbally communicate their needs. With proper training and supports, those who are providing care to someone who is engaging in challenging behaviors are able to understand that these behaviors are a means of communication. They can learn the meaning of certain behaviors and respond appropriately. The behaviors can be the result of many things, such as pain, illness, fear, frustration, confusion, hunger, thirst, temperature, noise, or a change in environment. Medical

problems often complicate behavioral problems. The response to challenging behaviors by family members, caregivers, health care providers, and law enforcement can either de-escalate these behaviors or can make them worse.

To effectively address a problem, one must know the cause. In the case of a person with dementia, to know the cause of challenging behaviors requires knowledge of the person behind the disease. Understanding the experience from the person's perspective is the key to preventing or de-escalating challenging behaviors in most cases. Each individual is unique, and the relationship between a caregiver and a person with a dementia is essential. Without training and supports, even family members or others who may know the person with dementia well, will not readily discern what is causing the challenging behavior or how to fix it.

A diagnosis of dementia does not explain every problem. Rather, dementia may obscure the real problem. Knowledge of the person's life experiences, especially any trauma or life changing events, can sometimes clarify the cause of challenging behaviors. Person-centered care is essential for this population. Best practices exist for preventing and responding appropriately to persons with dementia who exhibit challenging behaviors. These practices greatly improve the capacity of caregivers and other stakeholders to react to the changing needs of persons with dementia and improve quality of life for them and the households in which they live.

A colleague told me a story about an elderly woman at the assisted living facility where she had worked caring for people with dementia. The woman was admitted to the facility for a short stay while her family, who cared for her, went on an extended vacation. She was in the middle stages of the disease, was incontinent, and had difficulty communicating verbally. The woman was described as a very passive and pleasant woman. However, the first time the staff attempted to give her a shower she had a very negative reaction and refused to get in the shower. The staff decided to try again later. The next attempt to give the woman a shower was met with an even stronger negative response, including striking a staff member. The staff resorted to sponge baths to keep her as clean as they could. When the family returned, they told the staff that the woman never takes showers, she always takes baths. They explained that she has always been afraid of getting in a shower due to trauma early in her life: the elderly woman, who was Jewish, had grown up in Nazi Germany. There was a reason for her behavior, but her dementia prevented her from explaining that she wanted a bath and not a shower.

It is well established that removing a person with dementia from the environment with which he or she is familiar is likely to exacerbate difficult or challenging behaviors. This is the case when removal is sudden and in response to challenging behaviors with which the family member or caregiver can no longer cope. Use of physical force under these circumstances invariably has a negative effect.

In addition, the use of psychotropic medications as a response to challenging behaviors is not appropriate for people with dementia. They have limited effectiveness and may be harmful when used in this population. The Food and Drug Administration has issued

black box warnings for the use of these medications in people with dementia. Medications serve as a restraint when their effect is to sedate or impair motor function. They often mask the underlying cause of the challenging behavior making it more difficult to determine and address its cause.

The Division of Long Term Care administers a variety of programs that serve people with dementia in the community. In addition to fee-for-service Medicaid reimbursement for nursing homes and personal care or home health care, there are several long term care programs that operate under Medicaid Home and Community-Based Services waivers from the Centers for Medicare and Medicaid Services that are intended to support individuals in community settings. The original waiver programs, the Community Options Program, or COP, and the Community Integration Program, or CIP, are still operating in fifteen counties. In the remainder of the state, Family Care and IRIS serve persons with long term care needs in the most cost effective settings. Family Care and the similar Partnership program are managed care programs through which the Managed Care Organizations receive a capitated payment to purchase or provide a full range of home and community supports coordinated by a multi-disciplinary team. IRIS is a self-directed long term care program that provides a budget to the consumer or family caregiver to provide the necessary range of services and supports. Individuals who are enrolled into these programs are provided services in the least restrictive setting possible to meet their needs. Not all older people or people with dementia are financially eligible for Medicaid. Ultimately, when it becomes necessary to purchase care at home or in a facility, the costs of care can reduce the person's financial resources to a level of poverty that qualifies them for Medicaid coverage for nursing home long term care, Family Care, or IRIS.

The Division of Long Term Care is increasing its efforts to identify people with dementia, regardless of financial eligibility for funded long-term care, and to support the person and his or her family caregivers so that the person can remain at home for as long as possible. The Department's goal is to provide supports and interventions that help avoid or postpone the need for costly long term care.

As part of this effort, the Division of Long Term Care oversees the development and operation of 38 Aging and Disability Resource Centers, or ADRCs, that provide expert and unbiased information and counseling about programs and services. As part of the Department's long term care sustainability efforts, resources will be extended to selected Aging and Disability Resource Centers to pilot Alzheimer's interventions for family caregivers and persons who may have dementia.

The Division administers two caregiver support programs statewide, the Alzheimer's Family and Caregiver Support Program and the National Family Caregiver Support Program. The programs provide a limited amount of financial support for the caregivers of individuals living in the community. These service dollars can be used to provide supportive services, assistive technology, respite care, and other services that help family caregivers to continue to provide the care their loved ones need.

Aging and Disability Resource Centers are able to provide cognitive screening for people who show signs of cognitive decline. Screening for cognitive impairment can help identify people who have Alzheimer's disease early in the disease process. Alzheimer's disease is a very slowly progressive disease that is now thought to begin in a person's 40s or 50s. The rate of cognitive decline happens so slowly that symptoms do not become apparent until later in life when the disease begins to interfere with daily tasks.

A new dementia care specialist position being created in several Aging and Disability Resource Centers will provide two evidence-based interventions, the LEEPS program for individuals in the early stages of Alzheimer's disease or other dementias and the Memory Care Connections program to support caring for someone with dementia at home. These programs, which are funded by federal grants, do not provide service funding for individuals, but rather provide individuals with the tools to take control of their circumstances and manage their situation.

The LEEPS program is an evidence-based exercise and socialization program for people in the early stages of dementia. Numerous studies have shown the effectiveness of exercise in individuals with dementia in maintaining functional ability, both physically and cognitively. An individualized exercise program is developed and a volunteer accompanies the person to exercise and performs simple cognitively stimulating activities with the person.

The Memory Care Connections program is based on research that demonstrated that when family caregivers are supported with the knowledge, tools, and skills to provide care to a loved one with dementia who can no longer communicate in the way to which the family is accustomed, two things happen: caregiver stress is reduced and individuals with dementia are able to avoid institutionalization or delay institutional care for an average of eighteen months. The Memory Care Connections program also includes the development of a plan by the caregiver's family and friends to help support the caregiver.

Finally, the Division of Long Term Care has applied for a three-year federal grant to develop a community-wide approach to preventing neglect and abuse of older persons with Alzheimer's disease and other dementias who exhibit behavioral challenges. The project proposes to pilot for community dwelling individuals a set of interventions adapted from an evidence-based model used in nursing homes. The interventions seek to enable caregivers to assess and manage challenging behaviors by addressing unmet needs that give rise to behaviors, rather than restraining people with psychotropic medications.

Thank you for providing the opportunity for the Division of Long Term Care to be part of the discussion about these important issues. I will be happy to respond to any questions from the committee.