



Greater Wisconsin
Agency on Aging Resources, Inc.

**Testimony of
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**Before the Speaker's Task Force on Alzheimer's and Dementia
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Chairperson Rohrkaste, Vice-Chairperson Hesselbein and members of the Task Force on Alzheimer's and Dementia:

Thank you for this opportunity to testify today on policy initiatives for improving the care of those experiencing Alzheimer's and dementia, as well as their caregivers. My name is Janet Zander. I am the Advocacy & Public Policy Coordinator for the Greater Wisconsin Agency on Aging Resources, one of three Area Agencies on Aging in Wisconsin. We provide training and technical assistance to support the successful delivery of aging programs and services in 70 counties (all but Dane and Milwaukee) and the 11 tribes in Wisconsin. I am also a member of the Wisconsin Aging Advocacy Network (WAAN), a collaborative group of older adults and professional aging associations and organizations – including the Wisconsin Association of Area Agencies on Aging, the Wisconsin Association of Senior Centers, the Wisconsin Association of Nutrition Directors, the Wisconsin Association of Benefit Specialist, the Aging & Disability Professionals Association of Wisconsin (representing aging unit/ADRC directors and managers), the Wisconsin Adult Day Services Association, the Alzheimer's Association SE Wis. Chapter and the Wisconsin Institute for Healthy Aging (WIHA).

As we all know, the costs of Alzheimer's disease and other dementias are high, robbing individuals of memories of who they are, where they have been and the contributions they have made. Leaving people surrounded by "strangers," even if these people are those they loved most dearly. Recent studies have also shown the costs associated with caring for people with dementia far exceed costs associated with both heart disease and cancer, which can also involve long periods of decline before death. Dementia, has no effective treatments to slow its course, yet health care costs in the last five years of life, are by far, the most expensive for persons with dementia. For patients on Medicare, the average total cost of care for a person with dementia over the five years of a recent study was \$287,038, patients with heart disease or cancer had costs around \$174,000. Of those costs, Medicare paid almost the same amount for patients with each of those diseases (close to \$100,000), but dementia patients had many more expenses that were not covered by Medicare. The average out-of-pocket cost for a patient with dementia was \$61,522 which is more than 80 percent higher than the cost for someone with heart disease or cancer. The need for constant supervision and help with basic activities like eating, dressing and bathing, significantly drive up costs, none of which are covered by Medicare. Many families end up spending most or all of the household assets on care, and often end up dipping into their own savings as well. According to a new study, family members and unpaid caregivers spend more than 100 hours a month, on average, assisting

older adults with dementia who live in the community and not in residential care or nursing homes. This is a significantly greater time commitment, on average, than for caregivers assisting older adults without dementia (73 hours/month). Added to these care needs, is the need for caregivers and others to assist with transportation needs. Giving up the car keys not only means losing independence; studies continue to demonstrate a lack of transportation contributes to poor health outcomes, isolation and depression.

We are pleased to see that funding to support continuation of the existing Dementia Care Specialists (currently there are 20 Dementia Care Specialists serving 26 counties) in select Aging and Disability Resource Centers (ADRCs) across the state has been recommended by the Governor. There are currently estimated to be 120,000 people living in Wisconsin with Alzheimer's disease or other related dementias. Approximately 25% of these individuals are currently residing in some type of residential care setting (nursing home or assisted living facility); the remaining 75% are living in private residences - many with the help of family members and other caregivers and many others with little or no help from family and friends. Data from the Wisconsin Alzheimer's Institute, as reported in the Wisconsin Department of Health Services' – Wisconsin Dementia Care Redesign: A Plan for a Dementia-Capable Wisconsin, revealed that 22% of people diagnosed with a dementia are living alone. The number of older adults living with Alzheimer's disease is expected to increase by 20% by 2020. Given the important evidence-based programs and support the Dementia Care Specialists offer for people with dementia and their caregivers, **we ask not only for your support to continue these valuable Dementia Care Specialist positions but also for support to expand Dementia Care Specialists into the remaining 46 counties and to support the initiatives outlined in the Dementia Care Redesign plan.** Support for the continued development of a more dementia-capable system of care is critical in order to provide appropriate, safe and cost-effective care to individuals throughout the course of the disease.

Despite the fact that transportation continues to be one of the most needed services identified in community needs assessments of older adults and people with disabilities, the Executive Budget does little to support the growing need. Elderly and Disabled Transportation Aids or the s.85.21 program is renamed Seniors & Individuals with Disabilities Specialized Transportation Aids in the proposed budget and provided a 1% inflationary increase (\$437,600 for the biennium). The tribal specialized transportation program (s.85.215) is flat funded, as is public transit. Public transit infrastructure plays a vital role in our economy, connecting community residents with jobs, shopping, medical facilities, schools, and recreation, and is especially critical for people who cannot or chose not to drive. Older adults overwhelmingly want to age in place, transportation is one service that helps make this possible. **We are requesting a 10% increase in funding for the s.85.21 program with annual increases to keep pace with a growing older adult population. More investment is also needed in both s.85.215 and public transit to meet increased needs and account for inflationary cost increases.**

Lastly, Wisconsin's ADRCs and aging units, with the help of the Wisconsin Institute for Healthy Aging (WIHA), are helping Wisconsin residents improve their health and quality of life through high-level evidence-based programs that are cost-effective and save health and long term care dollars. Program participants experience fewer encounters with the health care system including decreases in emergency department visits and hospitalizations. The number of people who could be served by these programs would significantly increase if greater resources were available. WIHA currently relies on grant funding and relationships with partner agencies to carry out their mission. Providing WIHA and its partners predictable, base funding would extend the reach of these interventions to the people who need them. **We request your support of a \$600,000 annual state budget appropriation for WIHA to provide funding for counties to expand program capacity and ensure more people get the interventions and to support WIHA's core services – maintain program licenses; research, develop and manage**

program infrastructure; train and support leaders and support local partners in recruiting participants; and collect and analyze data.

- 1.) Funding to support expansion of the Alzheimer's Family and Caregiver Program (AFCSP) and Dementia Care Specialist (DCS) program.**
- 2.) Increase level of support for family/informal caregivers – training, respite.**
- 3.) Resources to promote and support the development of dementia –capable systems and dementia-friendly (age-friendly) communities.**
- 4.) Protection of rights for individuals with Alzheimer's and dementia.**
- 5.) Creation of a statewide Guardian Misconduct Registry**

Representative Rohrkaste, Representative Hesselbein, and members of the Task Force, thank you for this opportunity to comment on these important issues and proposals. We look forward to continuing to work with you to shape public policy that improves the quality of life of older people throughout the state.