Dementia Care System Redesign Data: Estimated and Projected Wisconsin Dementia Population

A key priority of the Department of Health Services (DHS) under the direction of Secretary Kitty Rhoades, is to improve the quality of life for all who are affected by dementia, which is a growing population. This report conveys key data findings related to the Wisconsin Dementia Care System Redesign. It describes current estimates of the number of people with dementia in Wisconsin, the subset of that population served by Wisconsin’s Medicaid program, and a projection of the growth in the dementia population.

Information about the prevalence of dementia, circumstances of individuals with dementia, service capacity and utilization, as well as the cost and quality of dementia care, are critical to the implementation of the strategies that have been identified in the Dementia Care System Redesign Plan (the Plan). One strategy within the Research and Data section of the Plan is to develop and implement a data collection plan, including development of baseline measures and use of metrics for measuring progress in achieving goals.

The Plan includes strategies to better serve people with dementia in Wisconsin. DHS has a particular responsibility to develop effective strategies for serving people with dementia who are enrolled in Wisconsin’s Medicaid program. Baseline measures will include those related to outreach, detection, and awareness that are broadly applicable for all people with dementia in Wisconsin, as well as outcome and fiscal impact measures specific to people with dementia enrolled in Medicaid. The first step is to identify the total population of people with dementia in Wisconsin and the subset who are enrolled in Medicaid. This population is the basis for developing baseline measures, which will subsequently be updated to track progress on goals.

Current Estimate of Wisconsin Dementia Population and Medicaid Enrollment

Over five million Americans are living with Alzheimer’s and related dementias. According to 2015 Facts and Figures from the Alzheimer’s Association, Alzheimer’s disease is the sixth leading cause of death in the United States. It’s the only cause of death in the top ten that cannot be prevented, cured or slowed. Applying national prevalence rates to Wisconsin’s demographics, an estimated 115,000 individuals in Wisconsin have dementia.\(^1\) Through the use of our databases, DHS is able to identify that nearly 30,000 of the 115,000 people in Wisconsin with dementia are enrolled in Wisconsin Medicaid.

Among the Medicaid population, individuals are categorized by the type of Medicaid program they are enrolled in: Waiver, Institutional and Other Medicaid.

- **Waiver enrollees** are all those enrolled in a Long Term Care (LTC) Waiver programs, including:
  - Family Care and Partnership,
  - The IRIS (Include, Respect, I Self-Direct) Program, and
  - Community Integration and Community Options Programs (CIP and COP).\(^2\)
- **Medicaid Institutional residents** are individuals on Medicaid, not enrolled in a LTC Waiver, and residing in a skilled nursing facility or intermediate care facility that is paid for by Medicaid.

\(^1\) This estimate is based on household population as estimated by the DHS Office on Aging plus estimated nursing home residents with dementia. While dementia is under-diagnosed in the community, prevalence estimates are based on studies that test everyone in the study population for dementia (Alzheimer’s Association).

\(^2\) Medicaid enrollees in LTC waiver programs are categorized here regardless of where they reside, meaning that Family Care and Partnership enrollees residing in nursing homes are counted as LTC Waiver enrollees and not Institution residents.
Other Medicaid Enrollees are individuals on Medicaid not residing in an institution or enrolled in a LTC Waiver.

**Figure 1**

Wisconsin’s Medicaid programs serve 1 in 4 of the estimated 115,000 Wisconsin residents with dementia. The largest group of Medicaid enrollees with dementia is those enrolled in LTC Waiver programs, followed by Institutional residents. Meeting the care needs of people with dementia does and will increasingly impact communities as a whole and our Medicaid programs in particular.

**Future Projections of Wisconsin Dementia Population and Medicaid Enrollment**

The number of Americans with Alzheimer’s disease and related dementias will grow each year as the size and proportion of the U.S. population age 65 and older continues to increase. National projections from the Alzheimer’s Association estimate Wisconsin’s growth rate to be 18.2 percent over the next 10 years, and doubling by 2040. It is this projected growth that creates a critical need to assess and improve our care systems for individuals now and into the future.

If the proportion of individuals with dementia that are Medicaid eligible remains a constant 25 percent, this population will grow from just fewer than 30,000 to more than 60,000 in the next 25 years.
As the numbers of people affected by Alzheimer’s disease and related dementia continues to grow, effective strategies for meeting their needs and the needs of their caregivers require development and expansion to keep pace.

This projected growth is at the core of the redesign of the Dementia-Capable system of care in Wisconsin.