

# Caring for Pennsylvanians with Dementia and Related Disorders: An Analysis of Needs and Capacity in Rural Areas, 2024 to 2034

By: Dara P. Bourassa, Ph.D., Shippensburg University of Pennsylvania;  
Sara A. Grove, J.D., Ph.D., Duquesne University.

This research project examines important questions regarding the potential demand for care for individuals living with Alzheimer's disease or a related disorder (ADRD) in rural Pennsylvania. By 2040, this study projects there will be approximately 133,000 more Pennsylvanians diagnosed with Alzheimer's, as the size of the population age 65 and older increases by over 23%. In most rural counties, the proportion of the population with Alzheimer's will exceed the overall state rate. Based on trends in data, the Commonwealth's capacity to care for individuals with dementia-related disorders in facilities is limited. A significant amount of care is provided to persons in their homes, and that need will grow. Interviews and surveys with professionals and care workers confirm ongoing challenges in providing adequate levels of staffing and training to deliver the home care for which patients are eligible. Policy considerations focus on additional supports to address the burdens facing family caregivers and the inadequate supply of paid caregivers.

## Methods

This study uses secondary data from a variety of resources to project the potential demand for care for individuals living with Alzheimer's disease or a related disorder (ADRD) in Pennsylvania, as well as the capacity of the state to provide care. In addition, the study incorporates results from interviews with directors or senior-level staff from area agencies on aging that serve 11 counties. This is supplemented by interviews from samples of community advo-

cates and family caregivers, as well as surveys of direct care workers and home care workers. This primary research helps to identify potential gaps that exist in the network providing dementia care in Pennsylvania, and the challenges facing counties over the next decade. In addition to suggestions from interviewees and survey respondents, selected information on innovative programs and other states' policies is included to help inform potential policy solutions.

## Key Findings

At present, the Commonwealth is ill-equipped to address the needs of individuals with Alzheimer's disease with its network of long-term care facilities. Individuals living in rural counties have limited choices for institutional care, whether it is in a skilled nursing facility, personal care home, or assisted living residence. Twenty-three counties have two or fewer skilled nursing facilities with dedicated units for individuals living with dementia, and 21 counties have no personal care facilities with specialized units. Based on recent data, the number of facilities and the overall capacity for patients is declining. Adding to the facilities' shortfall, income and retirement data show that most Pennsylvanians who need this level of care will not be able to pay for it from their own resources (Pennsylvania Health Care Association, 2024). The burden on familial caregivers is heavy; an inadequate supply of trained home care givers and adult care centers, particularly in rural areas, will continue to strain resources. There are often long waiting

lists for individuals who are eligible for services.

Data from interviews with directors from area agencies on aging and organizational advocacy organizations highlight challenges in providing care for individuals living with Alzheimer's or a dementia-related disorder. The directors were asked to provide their impressions as to whether the funds, from both public and private sources, allocated to their respective county/counties were sufficient to cover all the needs of the caregivers and those with ADRD. All directors answered they were not. The lack of home care workers is the top concern for the majority of those interviewed. Issues related to training, transportation in rural areas, and compensation were common themes. These views were shared by the surveyed agency direct care workers and home care workers. Family caregivers provided extraordinary insights into the challenges they face in taking care of their loved ones and the impact of caregiving on their lives. Family caregivers described challenges in finding resources to help them either understand the ADRD process or additional programs and services that could help them with providing care.

### Policy Considerations

Based upon recommendations from the area agencies on aging, organizational stakeholders, and family caregivers, there are policy considerations in three areas: program eligibility for family members whose loved ones are living with a dementia diagnosis; program and service improvements for those individuals

needing care and those individuals providing care; and additional education and training to support families and reduce risk factors associated with dementia.

Some selected considerations include:

- Changes in eligibility for caregiver support programs such as the Community HealthChoices Program, such that family members with Power of Attorney are not de facto prohibited from receiving benefits. Other states provide more flexibility than Pennsylvania does.

- Given the low wages, difficulty attracting an adequate workforce, and the large number of hours of unpaid care in the economy, explore the possibility of tax credits for those who work in the long-term care industry or as family caregivers.

- Create a tax-free avenue for individuals to save for long-term care, similar to the PA ABLE Program that exists for individuals with disabilities.

- Review the process for licensing adult day care centers and provide resources from the PA Department of Aging with the goal of facilitating the creation of new centers. This will relieve the burden on family caregivers and potentially reduce the need for full-time institutional care.

- Implement the concept of a "warm handoff" between physicians and social services at the time of diagnosis.

- Expand training requirements for paid caregivers, provide additional training for family caregivers, and share more information about Alzheimer's disease and its progression with the community as a whole.

### Center for Rural Pennsylvania Board of Directors

**Chairman**, *Senator Gene Yaw*

**Vice Chairman**, *Representative Eddie Day Pashinski*

**Secretary**, *Dr. Nancy Falvo*, Pennsylvania Western University Clarion

**Treasurer**, *Stephen M. Brame*, Governor's Representative

*Senator Judy Schwank*

*Representative Dan Moul*

*Richard Esch*, University of Pittsburgh

*Dr. Timothy Kelsey*, Pennsylvania State University

*Shannon M. Munro*, Pennsylvania College of Technology

*Dr. Charles Patterson*, Shippensburg University of Pennsylvania

*Susan Snelick*, Northern Pennsylvania Regional College

*Darrin Youker*, Governor's Representative

*Dr. Jeffrey Hyde*, Penn State Extension



### Center for Rural Pennsylvania Staff

*Dr. Kyle C. Kopko*, Executive Director

*Dr. Laura R. Dimino*, Assistant Director

*Michaela Miller*, Quantitative Data Analyst

*Katie Park*, Communications Manager

*Kaitlyn Goode*, Data Visualization Specialist

*Linda Hinson*, Office Manager