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.

Abstract: 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.

Key words: Alzheimer's disease, dementia, rural communities

This project was sponsored by a grant from the Center for Rural Pennsylvania, a legislative agency of the Pennsylvania General Assembly. The Center for Rural Pennsylvania is a bipartisan, bicameral legislative agency that serves as a resource for rural policy within the Pennsylvania General Assembly. It was created in 1987 under Act 16, the Rural Revitalization Act, to promote and sustain the vitality of Pennsylvania's rural and small communities. Information contained in this report does not necessarily reflect the views of individual board members or the Center for Rural Pennsylvania. For more information, contact the Center for Rural Pennsylvania, 625 Forster St., Room 902, Harrisburg, PA 17120, (717) 787-9555, www.rural.pa.gov.

Executive Summary

According to a 2014 report from the Pennsylvania Alzheimer's Disease State Planning Committee, "[r]ural Pennsylvanians are, on average, older, poorer, and with greater health care needs than those in urban areas, yet there are few primary care providers, nursing homes, and home and community-based services available" (Pennsylvania Department of Aging, 2014). Several years later, the goals to improve the outlook for individuals living with Alzheimer's disease and related disorders (ADRD) were largely unmet (Deppin, 2021). The Alzheimer's Association reports that in "2020, 280,000 people in Pennsylvania aged 65 and older have been diagnosed with Alzheimer's. By 2025, this number is expected to increase to 320,000 diagnoses" (Alzheimer's Association, 2022). As life expectancy remains constant or increases and new screening techniques that detect dementia-related disorders become routine (Yahaya, 2022), the number of individuals who need ADRD-related care services will increase.

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. Both smoking and obesity increase the risk of Alzheimer's disease for Pennsylvanians. This is of particular note for rural counties; over 90% have rates of smoking higher than the statewide average, and obesity rates at or above the statewide 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 advocates 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, a number of 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.

Table of Contents

Introduction

According to the 2014 report from the Pennsylvania Alzheimer's Disease State Planning Committee, "[r]ural Pennsylvanians are, on average, older, poorer, and with greater health care needs than those in urban areas, yet there are few primary care providers, nursing homes, and home and community-based services available" (Pennsylvania Department of Aging, 2014). Eight years later, the goals to improve the outlook for individuals living with Alzheimer's disease and related disorders (ADRD) were largely unmet (Deppin and Rihl, 2021). The Alzheimer's Association reports that in "2020, 280,000 people in Pennsylvania aged 65 and older have been diagnosed with Alzheimer's. By 2025, this number is expected to increase to 320,000 diagnoses (Alzheimer's Association, 2022). As life expectancy remains constant or increases and new screening techniques that detect dementia-related disorders become routine (Yahaya, 2022), the number of individuals who need ADRD-related care services will increase, and the need for support services for caregivers will intensify.

Dementia Prevalence and Options for Care

Individuals living with dementia confront daily challenges in performing routine activities that healthy individuals take for granted (dressing, bathing, and eating, as examples). Dementia does not strike overnight; instead, it gradually worsens as time passes. Eventually, an individual with the disease becomes dependent on others to provide care before they die. According to Scheltens, et al. (2021), dementia is the fifth leading cause of death in high-income countries.[1]

Alzheimer's disease is the most common form of dementia, accounting for between 60 to 80 percent of dementia diagnoses (Dumurgier and Sabia, 2021). According to the Alzheimer's Association (2023), the number of Americans living with Alzheimer's disease is projected to increase by 18 percent from 2020 to 2025. This increase is largely attributed to the growing numbers of Baby Boomers, those born from 1946 to 1964. Other projections done by for the Commonwealth show an increase over the same time period, albeit slightly smaller at 14 percent (Boden, 2023).

The growing number of individuals living with some form of dementia has increased demands for care in skilled nursing facilities, personal care homes, and assisted living residences (ALRs) while the opportunities available for institutional care have declined.[2] Data from the Pennsylvania Department of Health (2000) showed that Pennsylvania had 775 skilled nursing homes, with 95,083 licensed beds, while the Pennsylvania Department of Public Welfare (2002) licensed 1,786 personal care homes with a capacity of 79,929 licensed beds. Over the last two decades, the number of licensed nursing

[1] The article by Scheltens and co-authors provides a clinical look at the progression and pathology of Alzheimer's disease.

[2] Closures continue to affect long-term facilities. See Kris B. Mamula (June 9,2024) "Bankruptcies, closures rock senior care across Pennsylvania," *Pittsburgh Post-Gazette*, retrieved from https://www.post-gazette.com/business/healthcare-business/2024/06/09/senior-care-centers-bankruptcy-pennsylvania/stories/202406090042. One source of data: Association of Pennsylvania Nonprofit Senior Services (PANPHA) (2002). "Long-term Care Statistics and Information," Mechanicsburg, Pennsylvania.

homes and personal care homes as well as their capacities have declined. According to the Pennsylvania Health Care Association (PHCA) (2024), that trend is continuing. Pennsylvania has approximately 700 skilled nursing homes, with a current census of over 80,000 residents. Just over 1,200 licensed personal care homes serve another 46,500 residents while the number of ALRs has remained small (35) since licensing began in December 2015.

Current estimates show that among adults 65 to 84 years old, one out of three are receiving care in a nursing facility for a dementia diagnosis (Eisenmann, et. al, 2020; Mather and Scommegna, 2020). Nearly 65 percent of these individuals rely on Medicaid to fund their care as they have depleted their savings, sold their primary residence, expended other resources, and have limited incomes (Pennsylvania Health Care Association, 2022). According to data from the Pennsylvania Department of Human Services (2021), older adults and individuals with disabilities account for 78 percent of Medicaid's annual total program costs, with an average of $7,811 being spent per beneficiary.

The challenge for providing care in institutional facilities is the cost. In Pennsylvania, the average shared room daily cost is higher than the national average of $342 per day or $124,841 annually. Regionally, there are differences in the cost of nursing home care. In the rural areas of Pennsylvania, it can cost an individual $107,310 (Bloomsburg area) to $135,780 (Gettysburg area) a year for a shared room (American Council on Aging, 2022). "Nineteen percent of nursing home residents were eligible for Medicaid benefits before entering a nursing home. An additional nineteen percent will exhaust their personal assets and become eligible for Medicaid during their first year in a nursing home" (Pennsylvania Health Care Association, 2024). A challenge from the perspective of the facilities is that Medicaid payments to skilled nursing facilities do not meet the expenses these facilities incur. The shortfall, on average, is $47.85 per person per day, which amounts to a total of $631.6 million annually (Private correspondence with LeadingAge Pennsylvania (2019)).[3] This shortfall forced 12 skilled nursing facilities to close in the Commonwealth between June 2015 and June 2019, with three of the homes closing in rural areas (LeadingAge Pennsylvania, 2020).

For older adults who prefer or need to remain in their homes and "age in place" (Davis, 2021), care choices need to include programs not only for individuals who can self-pay, but also for individuals who rely on state and federal programs and services. The desire to "age in place" adds complexity because caregivers are no longer institutions which have regulations and guidelines to follow, but individuals who may lack formal training as caregivers and receive little to no financial support.

Developing programs that assist caregivers is a critical element in supporting a comprehensive network of aging service providers. To this end, there are three main programs that are offered in Pennsylvania to help meet the various needs of frail older adults and the people who provide care to them in their homes. Two programs, Help at Home (commonly referred to as the OPTIONS Program) and the Caregiver Support

[3] The shortfall was also reported by the American Health Care Association (2016) which noted that the Commonwealth "under funds nursing home care by an average of $9,000 per Medicaid resident per year" (Pennsylvania Health Care Association, 2024).

Program (CSP) are administered by the Pennsylvania Department of Aging (PDA) through the 52 Area Agencies on Aging (AAA). The OPTIONS Program provides care management services to individuals aged 60 and over, who have been determined to have unmet needs that impact their daily functioning. The Caregiver Support Program "provides resources and assistance to individuals who assume the primary responsibility for the provision of care to encourage a healthy, ongoing relationship with their care receiver" (Pennsylvania Department of Aging, 2024). The third main program, Community HealthChoices (CHC), is administered by the Pennsylvania Department of Human Services (DHS) and is the managed care program to increase "opportunities for older Pennsylvanians and individuals with physical disabilities to remain in their homes" (Pennsylvania Department of Human Services, 2024).

The programs sponsored by the PDA do not have financial eligibility requirements; however, the amount that the local AAA will contribute or reimburse for services is based on the total gross income and household size of the care receiver, using the current Federal Poverty Guidelines. Therefore, "depending on [individual's] income, they may be required to contribute towards the cost of their services based on a sliding co-payment scale" (Pennsylvania Department of Aging, Caregiver Support Program (2024) and Pennsylvania Department of Aging, Help at Home (OPTIONS) (2024). Community HealthChoices is funded through Medicaid/Medical Assistance and functions independently from the PDA. Table 1 provides more information about these programs.

Table 1: Information About Caregiver Support Program, Help at Home (OPTIONS), and Community HealthChoices

Program Name	Caregiver Support Program-Category 1	Help at Home (OPTIONS Program)	Community HealthChoices Program
Program Description	Provides resources and assistance to individuals who assume the primary responsibility for the provision of care to encourage a healthy, ongoing relationship with their care receiver	Provides assistance to Pennsylvania residents, age 60 and older who would like to stay in their home	Mandatory managed care program for dually eligible individuals and individuals with physical disabilities
Administered Through	Pennsylvania Department of Aging and Local Area Agencies on Aging	Pennsylvania Department of Aging and Local Area Agencies on Aging	Pennsylvania Department of Human Services
Requirements to Enroll and Participate	• Caregiver is an individual age 18 and older • Care recipient is • An individual age 60 and older with functional deficits *or* • An individual of any age with Alzheimer's disease or related disorder	• Must live in Pennsylvania • Must be at least 60 years of age • Must be U.S. citizen or legal resident • Must be determined to have unmet needs that impact daily functioning • Serves those who are either financially or clinically ineligible for	• Care recipient must be 21 years old or over • Receiving both Medicare and Medicaid *or* LTSS in the Attendant Care, Independence, *or* Aging waivers, *or* services in the OBRA waiver *and* determined nursing clinically eligible *or* • Receiving care in a nursing home paid for by Medicaid

		Medical Assistance Long-Term Services and Supports	• Act 150 participant who is dually eligible for Medicare and Medicaid

Program Name	Caregiver Support Program-Category 1	Help at Home (OPTIONS Program)	Community HealthChoices Program
Financial Requirements for Program	No financial eligibility requirement, however, the amount of reimbursement is based on the total gross income and household size of the care receiver, using Federal Poverty Level guidelines	No income requirements to participate in the program. However, depending on an individual's income, they may be required to contribute towards the cost of their services based on a sliding co-payment scale	Individual must fall below the current year's Federal Poverty Level guidelines
Who Pays for Services?	Local Area Agencies on Aging	Local Area Agencies on Aging	Medicaid
Services Offered	Care Management Benefits Counseling Caregiver Education and Training Reimbursement for ongoing expenses for caregiving-related services or supplies, such as: • Respite Care • Consumable Supplies • Home Modifications • Assistive Devices	Adult Day Services Care Management In-Home Meals Personal Care Services Supplemental services may also be available based on the local Area Agency on Aging	Covers the same physical health benefits that are part of the Medicaid Adult Benefit Package today If eligible for LTSS, the individual can get all the services available by the Office of Long-Term Living

Program Name	Caregiver Support Program-Category 1	Help at Home (OPTIONS Program)	Community HealthChoices Program
Coordination of Services	Local Area Agencies on Aging	Local Area Agencies on Aging	Medicaid Managed Care Organizations • Keystone First • Pennsylvania Health and Wellness • UPMC Community HealthChoices

Sources: Montgomery County, Pennsylvania (2024); Pennsylvania Department of Aging (2024).

If paid care, either in an institutional or home setting is unavailable, family members, friends, and neighbors become the caregivers for individuals living with dementia. The Alzheimer's Association (2023) estimates that there are more than 400,000 unpaid caregivers across the state as of 2022.

While the U.S. Bureau of Labor Statistics (2023) reports that there are 213,020 home health and personal care workers in Pennsylvania, the Alzheimer's Association (2023) projects the need for an additional 40,000 home health and personal care workers by 2030 to care for persons aging in place. This estimate may appear high, but often, an individual has more than one caregiver. While challenging under the best of conditions, the COVID-19 pandemic prompted many direct care workers to opt for employment in other sectors. In addition, the low annual median income of less than $30,000 for this type of work makes it difficult to attract an adequate workforce (U.S. Bureau of Labor Statistics, 2022); therefore, we expect the Commonwealth will continue to face a serious labor shortage of home health and personal care workers.

Caring for an individual with dementia places enormous strain on the caregiver which also creates additional challenges for existing health care systems. Forty percent of caregivers have reported physical stress, with another 60 percent reporting emotional stress. As the Alzheimer's Association has documented, "caregivers of people with dementia note higher rates of depression than those caring for someone without dementia" (Boden, 2023). Caring for the caregiver requires programs that can relieve some of the burden, including professional care planning and coordination services, adult day services, and respite care. (Id.) Individual counseling and support groups can assist caregivers as they struggle with feelings of frustration and despair.

Methods

This research project utilizes both secondary quantitative data and primary qualitative data to assess key questions about dementia care in rural Pennsylvania. Secondary data from a variety of resources, including the Center for Rural Pennsylvania, the Pennsylvania Department of Health, the Centers for Disease Control, and the Alzheimer's Association,[4] is used 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. This data was collected by the research team.[5] Population projections from the Center for Rural Pennsylvania were used with prevalence rates from the Alzheimer's Association to prepare projections of the need for dementia care in Pennsylvania. Data on selected health factors associated with dementia-related disorders is also reviewed.

[4] The Alzheimer's Association uses data from the United States Census Bureau, the Chicago Health and Aging Project, and the Aging, Demographics, and Memory Study (ADAMS) to create its prevalence estimates. See the report, *2022 Alzheimer's Disease: Facts and Figures*, p. 19-21.

[5] Raw Excel data files have been provided to the Center for Rural Pennsylvania. Data was uploaded to SPSS for additional analysis.

In addition, the study incorporates results from interviews with directors or senior-level staff from area agencies on aging that serve 11 counties.

The research team conducted interviews over Zoom with the Area Agency on Aging Directors or a senior member of the staff using a semi-structured interview guide that was approved by the Shippensburg University Institutional Review Board (IRB) (see Appendix 1).[6] The purpose of the interviews overall is to identify potential gaps that exist in the network providing dementia care in Pennsylvania, and the challenges facing counties over the next decade. Table 2 lists the agencies who participated in this portion of the project.[7] This effort is supplemented by interviews from samples of community advocates and family caregivers, as well.

Table 2: Area Agencies on Aging Which Participated in Interviews

Participating Agency	Counties Served
Carbon County Area Agency on Aging	Carbon County
Columbia-Montour Aging Office, Inc.	Columbia and Montour Counties
Active Aging, Inc.	Crawford County
Cumberland County Aging & Community Services	Cumberland County
Southwestern Pennsylvania Area Agency on Aging	Fayette, Greene, and Washington Counties
Area Agency on Aging for Luzerne and Wyoming Counties	Luzerne and Wyoming Counties
Perry County Area Agency on Aging	Perry County

*Blair Senior Services assisted with recruitment of family caregivers.

While the leadership of the AAAs provided information on challenges faced with funding and recruitment of staff, the researchers also sought the perspective of the AAAs' direct care workers and home care workers.[8] Efforts to conduct Zoom interviews with members of these two groups proved fruitless. The research team developed a Qualtrics survey for distribution by AAA partner agencies and other stakeholders who offered assistance (Pennsylvania Association of Area Agencies on Aging and Angels on Call).[9] To encourage participation in the online survey, we offered home care workers the opportunity to enter a drawing for a $20 Amazon gift card. Information including the individual's name and mailing address was separated from the answers to the Qualtrics

[6] The recordings will be maintained according to the IRB protocol until three years after the completion of the study.

[7] Informally, the research team worked with the Blair County Area Agency on Aging to recruit family caregivers to interview.

[8] The U.S. Bureau of Labor Statistics has three occupational classifications of direct care workers which include a variety of names and titles, such as attendants, assisted living aides, home health and home care aides, nurse aides, certified nurse aides, nursing assistants. For purposes of this report, we use the term direct care workers to refer to individuals employed by AAAs in these capacities and home care workers for individuals employed or contracted through third-party providers.

[9] The survey provided to the agency direct care workers and home care workers contained the same questions. The agency direct care workers were not provided with an opportunity to enter into a drawing for a gift card because rules on gifts for county workers in one of the partner counties.

questions.[10] One hundred and fourteen direct care and home care workers responded to the surveys.

To provide answers about potential new policies, interview and survey participants were asked for their suggestions. In addition, the researchers conducted a systematic search (Bramer, et al., 2018) for innovative programs supported by states and not-for-profit organizations that support individuals living with a dementia-related disorder and their caregivers. After compiling the list of programs and determining their source of funding,[11] the researchers engaged with professionals working in the aging network to collect additional information about programs already having a foothold in the Commonwealth.

Results

Population Projections and County-Level ADRD Diagnoses

Population projections from 2020 (estimated) through 2040 (projected) were obtained from the Center for Rural Pennsylvania. While the total population in rural counties will decline from 3.38 million in 2020 to 3.27 million in 2040, the population age 65 and older in rural counties will increase from 709,051 in 2020 to 853,512 in 2040 (see Table 3).[12] These five-year age projections show that the population age 65 and older in the Commonwealth will increase by 23.5% between 2020 to 2040. The growth from 2020 to 2040 is on top of a 17.3% growth rate of Pennsylvanians aged 55 and older from 2010 to 2020. The growth in Pennsylvania's senior population was predominantly in urban counties with only four rural counties exceeding the statewide growth rate for individuals 65 and older (Butler, Centre, Monroe, and Perry) (see Table 4).

[10] Ten gift card recipients were selected and notified. Gift card recipients were asked to complete a release and return it in order to receive the gift card. One recipient provided an incorrect mailing address, so another recipient was selected.

[11] Appendix 4 provides a short summary of each program and its website.

[12] This statement is predicated on no changes in counties classified as "rural" by the Center for Rural Pennsylvania during this twenty-year time period.

Table 3: Population Projections Age 65 and Over by County, 2020 and 2040

County	2020	2040	County	2020	2040
Pennsylvania	2,436,990	3,110,811	**Juniata**	4,862	5,993
Adams	21,689	26,526	**Lackawanna**	43,231	51,630
Allegheny	242,794	288,995	**Lancaster**	104,214	125,124
Armstrong	14,947	17,689	**Lawrence**	19,409	22,225
Beaver	36,891	43,525	**Lebanon**	28,513	34,147
Bedford	11,065	12,721	**Lehigh**	63,491	86,966
Berks	75,221	102,264	**Luzerne**	64,440	79,656
Blair	25,619	30,234	**Lycoming**	22,733	27,154
Bradford	13,055	14,920	**McKean**	8,110	10,231
Bucks	125,657	170,924	**Mercer**	24,907	27,894
Butler	38,349	50,863	**Mifflin**	9,987	11,418
Cambria	30,895	34,013	**Monroe**	30,638	45,370
Cameron	1,277	1,282	**Montgomery**	155,198	205,921
Carbon	14,120	17,815	**Montour**	3,825	4,427
Centre	23,821	31,309	**Northampton**	61,546	76,961
Chester	90,781	131,357	**Northumberland**	19,810	22,844
Clarion	7,557	8,891	**Perry**	8,948	12,067
Clearfield	16,788	20,817	**Philadelphia**	223,567	325,383
Clinton	7,308	8,703	**Pike**	13,789	16,931
Columbia	12,811	15,475	**Potter**	4,048	4,221
Crawford	18,139	21,312	**Schuylkill**	29,759	35,975
Cumberland	48,820	63,309	**Snyder**	7,920	9,306
Dauphin	50,054	67,625	**Somerset**	17,078	18,997
Delaware	96,437	134,362	**Sullivan**	1,763	1,922
Elk	6,994	8,580	**Susquehanna**	9,239	10,524
Erie	50,925	62,276	**Tioga**	9,291	10,453
Fayette	28,124	33,017	**Union**	8,051	8,544
Forest	1,570	1,477	**Venango**	11,964	13,780
Franklin	31,035	39,082	**Warren**	9,162	10,406
Fulton	3,227	3,722	**Washington**	44,367	54,256
Greene	7,067	8,699	**Wayne**	12,657	14,066
Huntingdon	9,443	10,272	**Westmoreland**	82,878	95,604
Indiana	16,593	18,937	**Wyoming**	5,783	6,854
Jefferson	9,458	11,298	**York**	83,281	111,270

Table 4: Population Growth Rate Age 65 and Over by County, 2020 to 2040

County	Growth Rate 2020 to 2040	County	Growth Rate 2020 to 2040
Pennsylvania	21.7%	**Juniata**	18.9%
Adams	18.2%	**Lackawanna**	16.3%
Allegheny	16.0%	**Lancaster**	16.7%
Armstrong	15.5%	**Lawrence**	12.7%
Beaver	15.2%	**Lebanon**	16.5%
Bedford	13.0%	**Lehigh**	27.0%
Berks	26.4%	**Luzerne**	19.1%
Blair	15.3%	**Lycoming**	16.3%
Bradford	12.5%	**McKean**	20.7%
Bucks	26.5%	**Mercer**	10.7%
Butler	24.6%	**Mifflin**	12.5%
Cambria	9.2%	**Monroe**	32.5%
Cameron	0.4%	**Montgomery**	24.6%
Carbon	20.7%	**Montour**	13.6%
Centre	23.9%	**Northampton**	20.0%
Chester	30.9%	**Northumberland**	13.3%
Clarion	15.0%	**Perry**	25.8%
Clearfield	19.4%	**Philadelphia**	31.3%
Clinton	16.0%	**Pike**	18.6%
Columbia	17.2%	**Potter**	4.1%
Crawford	14.9%	**Schuylkill**	17.3%
Cumberland	22.9%	**Snyder**	14.9%
Dauphin	26.0%	**Somerset**	10.1%
Delaware	28.2%	**Sullivan**	8.3%
Elk	18.5%	**Susquehanna**	12.2%
Erie	18.2%	**Tioga**	11.1%
Fayette	14.8%	**Union**	5.8%
Forest	-6.3%	**Venango**	13.2%
Franklin	20.6%	**Warren**	12.0%
Fulton	13.3%	**Washington**	18.2%
Greene	18.8%	**Wayne**	10.0%
Huntingdon	8.1%	**Westmoreland**	13.3%
Indiana	12.4%	**Wyoming**	15.6%
Jefferson	16.3%	**York**	25.2%

Appendix 2 provides a map and data table from the Alzheimer's Association (2023) of prevalence estimates for each county in Pennsylvania in 2020. The data show the counties with the highest prevalence of Alzheimer's disease are more likely to be urban rather than rural counties. Among Pennsylvania's forty-eight rural counties, only three counties are at or exceed the statewide prevalence rate of 11.5% (Mercer 11.5%, Union, 11.8%, and Montour, 12.2%).

Beyond the prevalence rate, the Pennsylvania Department of Health publishes an age-adjusted death rate due to Alzheimer's disease. These rates, as well as the rank of Alzheimer's disease in each county, are found in Table 5. Statewide, Alzheimer's disease is the sixth leading cause of death. Interestingly, Alzheimer's disease is the fourth leading cause of death in three rural counties (Elk, Forest, and Mercer) and the fifth leading cause of death in seven rural counties (Adams, Bradford, Centre, Clinton, Perry, Somerset, and Wayne) and one urban county (Lancaster).

Table 5: Age-Adjusted Death Rate, Alzheimer's Disease and Rank in Cause of Death by County, 2020

County	Age-Adjusted Death Rate	Rank in Cause of Death	County	Age-Adjusted Death Rate	Rank in Cause of Death
Pennsylvania	22.7	6	**Juniata**	17.0	7
Adams	32.4	5	**Lackawanna**	25.0	6
Allegheny	22.9	6	**Lancaster**	31.3	5
Armstrong	26.8	7	**Lawrence**	29.7	6
Beaver	32.4	6	**Lebanon**	20.1	6
Bedford	21.1	7	**Lehigh**	26.2	6
Berks	17.9	7	**Luzerne**	20.0	7
Blair	27.7	6	**Lycoming**	29.3	6
Bradford	32.0	5	**McKean**	14.5	10
Bucks	20	6	**Mercer**	31.5	4
Butler	29.9	6	**Mifflin**	15.8	9
Cambria	26.0	6	**Monroe**	24.5	7
Cameron	No data	No data	**Montgomery**	19.1	6
Carbon	23.8	7	**Montour**	28.8	6
Centre	27.2	5	**Northampton**	20.5	7
Chester	18.5	6	**Northumberland**	28.1	6
Clarion	29.1	7	**Perry**	34.5	5
Clearfield	28.4	7	**Philadelphia**	14.3	9
Clinton	38.6	5	**Pike**	14.1	7
Columbia	23.0	6	**Potter**	No data	No data
Crawford	41.1	6	**Schuylkill**	18.8	8
Cumberland	17.2	6	**Snyder**	18.3	7
Dauphin	16.2	8	**Somerset**	41.2	5
Delaware	15.7	7	**Sullivan**	17.4	7
Elk	43.8	4	**Susquehanna**	21.9	7
Erie	22.5	8	**Tioga**	12.2	8
Fayette	17.2	8	**Union**	16.3	7
Forest	44.3	4	**Venango**	18.7	7
Franklin	24.0	7	**Warren**	11.5	10
Fulton	25.5	6	**Washington**	21.8	7
Greene	20.1	7	**Wayne**	34.0	5
Huntingdon	20.3	7	**Westmoreland**	20.2	7
Indiana	16.4	9	**Wyoming**	16.1	8
Jefferson	22.0	7	**York**	23.7	6

In its 2023 report, the Alzheimer's Association discussed risk factors associated with the disease. These factors include age, genetics, and family history, and modifiable risk factors such as smoking, diet, physical activity, cardiovascular disease, education, social and cognitive engagement, and traumatic brain injury. The report notes that the greatest risk factors are the onset of older age and genetics.

For this study, age will be used first to project the number of cases of Alzheimer's disease in each county over the period from 2025 to 2040. The Alzheimer's Association's prevalence rates[13] were applied to the population projections from the Center for Rural Pennsylvania. The current (2020) prevalence rates are included in Table 6.

Table 6: Alzheimer's Disease Prevalence Rates by Age Group, 2020

Age Group	Prevalence Rate
65 – 74	5.0%
75 – 84	13.1%
85 and Older	33.3%

Source: Alzheimer's Association (2023).

Table 7 applies the prevalence rates to the population data from 2020 through 2040 and shows the percentage of Alzheimer's cases in each of Pennsylvania's counties. Based on these estimates, 268,990 Pennsylvanians were living with Alzheimer's disease in 2020 with the number projected to increase to 401,688 statewide in 2040.[14]

[13] Prevalence rates take the total number of cases of a disease divided by the total population which then is standardized per 100,000 persons.

[14] To calculate the number of Alzheimer's disease cases in each county, the population over 65 years of age was divided into three groups: individuals aged 65 – 74, 75 – 84, and 85 and older. The rates from Table 7 were applied to their respective groups. For example, in Adams County in 2020, there were 12,945 individuals between 65 and 74 years of age. The rate for this group, according to the Alzheimer's Association, is 5%. Therefore, we estimate that 647 individuals in Adams County between 65 and 74 years of age have Alzheimer's disease. This same methodology was used for the other two age groups, applying the percentage of 13.1% to the group 75 - 84 and 33.3% to the group 85 and older. The number of individuals in each of the three age groups was aggregated to reach the county total.

Table 7: Projections of Alzheimer's Disease by County Based on Age, 2020 and 2040

County	Number of Cases 2020	Percentage of Population 2020	Number of Cases 2040	Percentage of Population 2040
Pennsylvania	268,990	11.0%	401,688	12.9%
Adams	2,275	10.5%	3,504	13.2%
Allegheny	27,254	11.2%	38,266	13.25
Armstrong	1,627	10.9%	2,360	13.3%
Beaver	4,078	11.1%	5,870	13.5%
Bedford	1,238	11.2%	1,652	13.0%
Berks	8,380	11.1%	12,865	12.6%
Blair	2,823	11.0%	4,024	13.3%
Bradford	1,405	10.8%	2,027	13.6%
Bucks	13,824	11.0%	21,833	12.8%
Butler	4,178	10.9%	6,630	13.0%
Cambria	3,435	11.1%	4,634	13.6%
Cameron	135	10.6%	182	14.2%
Carbon	1,497	10.6%	2,334	13.1%
Centre	2,598	10.9%	3,944	12.6%
Chester	9,761	10.8%	16,227	12.4%
Clarion	824	10.9%	1,165	13.1%
Clearfield	1,845	11.0%	2,714	13.0%
Clinton	811	11.1%	1,139	13.1%
Columbia	1,392	10.9%	2,037	13.2%
Crawford	1,907	10.5%	2,905	13.6%
Cumberland	5,402	11.1%	8,160	12.9%
Dauphin	5,331	10.7%	8,566	12.7%
Delaware	10,750	11.1%	16,973	12.6%
Elk	778	11.1%	1,125	13.1%
Erie	5,534	10.9%	8,197	13.2%
Fayette	3,051	10.8%	4,397	13.3%
Forest	155	9.9%	223	15.1%
Franklin	3,452	11.1%	5,021	12.8%
Fulton	342	10.6%	467	12.5%
Greene	733	10.4%	1,149	13.2%
Huntingdon	1,022	10.8%	1,382	13.5%
Indiana	1,783	10.7%	2,576	13.6%
Jefferson	1,043	11.0%	1,519	13.4%

County	Number of Cases 2020	Percentage of Population 2020	Number of Cases 2040	Percentage of Population 2040
Juniata	546	11.2%	787	13.1%
Lackawanna	4,865	11.3%	6,773	13.1%
Lancaster	12,256	11.8%	16,415	13.1%
Lawrence	2,206	11.4%	2,999	13.5%
Lebanon	3,237	11.4%	4,454	13.0%
Lehigh	7,010	11.0%	10,866	12.5%
Luzerne	7,227	11.2%	10,277	12.9%
Lycoming	2,514	11.1%	3,610	13.3%
McKean	887	10.9%	1,346	13.2%
Mercer	2,866	11.5%	3,755	13.5%
Mifflin	1,132	11.3%	1,518	13.3%
Monroe	3,033	9.9%	5,714	12.6%
Montgomery	17,672	11.4%	26,239	12.7%
Montour	454	11.9%	595	13.4%
Northampton	7,067	11.5%	9,952	12.9%
Northumberland	2,194	11.1%	3,083	13.5%
Perry	895	10.0%	1,586	13.1%
Philadelphia	24,098	10.8%	39,824	12.2%
Pike	1,411	10.2%	2,266	13.4%
Potter	444	11.0%	595	14.1%
Schuylkill	3,290	11.1%	4,691	13.0%
Snyder	934	11.8%	1,195	12.8%
Somerset	1,919	11.2%	2,585	13.6%
Sullivan	187	10.6%	275	14.3%
Susquehanna	969	10.5%	1,445	13.7%
Tioga	1,005	10.8%	1,421	13.6%
Union	954	11.8%	1,157	13.5%
Venango	1,289	10.8%	1,879	13.6%
Warren	994	10.8%	1,417	13.6%
Washington	4,806	10.8%	7,168	13.2%
Wayne	1,287	10.2%	1,970	14.0%
Westmoreland	9,079	11.0%	12,844	13.4%
Wyoming	589	10.2%	922	13.5%
York	9,012	10.8%	13,997	12.6%

Table 7 also includes the percentage of the county's population projected to have Alzheimer's disease in 2020 and 2040. Statewide in 2020, 11% of the Commonwealth's population was projected to have Alzheimer's disease; by 2040, the percentage increases to 12.9%. Looking at 2020, in 16 rural counties the proportions of their population with Alzheimer's disease exceeded the statewide proportion. By 2040, the number of rural counties which exceed the statewide population percentage with Alzheimer's disease balloons to 43 rural counties.[15] Over the twenty-year period, only two counties, Franklin and Union, experience a decline in the percentage of Alzheimer's disease cases.

For more than a decade, research has demonstrated a causal link between smoking and an increased risk for dementia, particularly Alzheimer's disease and vascular dementia (see Durazzo, Mattsson, and Weiner (2014)). "[C]urrent smokers were 30% more likely to develop dementia in general and 40% more likely to develop Alzheimer's disease" (Alzheimer's Research UK, n.d.). The Behavioral Risk Factor Surveillance System (BRFSS)[16] estimates the percentage of individuals who have risk factors such as smoking. Using the same methodology for estimating the number of individuals who have Alzheimer's disease, Table 8 shows the impact of smoking on the number of potential Alzheimer's disease cases in each county.[17]

According to BRFSS data (2023), 18.2% of Pennsylvanians are current smokers; this is above the nationwide percentage of 17.4%. Looking at the county-level data, 44 rural counties exceed the statewide percentage with the highest proportion of smokers in Forest (25.4%), Mifflin (23.3%), Fayette (23.2%), Juniata (22.7%), and Clearfield (22.5%) counties. Applying the risk factor of 40%, current smoking rates increase the number of Alzheimer's cases by 19,600, with 6,227 additional cases in the Commonwealth's rural

[15] The counties with greater proportions of their population with Alzheimer's disease in 2020 were: Bedford, Cambria, Clinton, Elk, Franklin, Juniata, Lawrence, Lycoming, Mercer, Mifflin, Montour, Northumberland, Schuylkill, Snyder, Somerset, and Union. By 2040, the following counties were added to this list: Adams, Armstrong, Blair, Bradford, Butler, Cameron, Carbon, Clarion, Clearfield, Columbia, Crawford, Fayette, Forest, Greene, Huntingdon, Indiana, Jefferson, McKean, Perry, Pike, Potter, Sullivan, Susquehanna, Tioga, Venango, Warren, Washington, Wayne, and Wyoming. Only two counties, Franklin and Union, saw the percentage of Alzheimer's disease cases decline.

[16] The Behavioral Risk Factor Surveillance System (BRFSS) is managed by the Centers for Disease Control and Prevention. It "collect[s] uniform, state-specific data on U.S. adults' health-related risk behaviors, chronic health conditions, and use of preventive services." See Centers for Disease Control and Prevention, Behavioral Risk Factor Surveillance System, retrieved from https://www.cdc.gov/brfss/index.html. This data is used by organizations such as the American Association of Retired Persons (AARP) as part of its "Livable Communities Project." See AARP, (2024), "AARP Network of Age-Friendly States and Communities," retrieved from https://www.aarp.org/livable-communities/network-age-friendly-communities/.

[17] Continuing with Adams County as the example, BRFSS estimates that 19.2% of Adams County residents are current smokers. The BRFSS estimate was multiplied by the population 65 years of age and over who are projected to have Alzheimer's disease (2,275). This value was then multiplied by 0.4, based on the research that suggests that smoking increases the risk of Alzheimer's disease by 40 percent. This calculation estimates that smoking increases the number of Alzheimer's disease cases in Adams County by 175.

counties.

Research has also shown a strong correlation between obesity and the onset of Alzheimer's disease.[18] Obesity is a national health epidemic with 32.5% of Americans considered obese using Body Mass Index (BMI) as the measure. Statewide, the percentage of obese Pennsylvanians mirrors the national percentage, but rural Pennsylvania's population has higher obesity rates. County-level data show that only 3 of the Commonwealth's 48 rural counties (Blair at 30.8%, Crawford at 31.8%, and Elk at 31.5%) have slightly lower obesity rates than the statewide percentage.

Studies estimate that obesity can increase dementia risk by approximately 30 percent. BRFSS evaluates obesity as another risk factor for the onset of multiple conditions; it calculates the percentage of individuals in each county who are obese. Table 8 shows the percentage of individuals who are obese in each county. Applying the same methodology as was done with age and smoking, Table 8 also shows an estimate of the impact of obesity on the number of Alzheimer's disease cases in each county.[19] Higher levels of obesity across Pennsylvania translate into increased numbers of Alzheimer's cases – an estimated 26,363 statewide – with 7,982 cases (about 30% of the total) in rural counties.

[18] See Alzheimer's Society (2024), "Obesity and dementia risk," retrieved from https://www.alzheimers.org.uk/about-dementia/managing-the-risk-of-dementia/reduce-your-risk-of-dementia/obesity.

[19] Finishing the example with Adams County, the estimate is an additional 231 cases of Alzheimer's disease based on the obesity rate of 33.9 percent and the risk factor of 30 percent.

Table 8: Estimates of the Impact of Smoking and Obesity on Projection of Alzheimer's Disease by County, 2020

County	Population Percentage Smoking	Increase in Cases from Smoking (Estimated)	Population Percentage Obesity	Increase in Cases from Obesity (Estimated)
Adams	19.2%	175	33.9%	231
Allegheny	15.6%	1701	32.5%	2657
Armstrong	21.4%	139	40.1%	196
Beaver	18.8%	307	34.7%	425
Bedford	21.8%	108	35.0%	130
Berks	19.0%	637	37.3%	938
Blair	20.1%	227	30.8%	261
Bradford	21.5%	121	36.8%	155
Bucks	15.4%	852	25.9%	1074
Butler	16.3%	272	33.2%	416
Cambria	20.1%	276	32.5%	335
Cameron	22.1%	12	35.0%	14
Carbon	21.2%	127	31.4%	141
Centre	15.9%	165	29.3%	228
Chester	13.6%	531	30.3%	887
Clarion	20.4%	67	35.2%	87
Clearfield	22.5%	166	34.4%	190
Clinton	20.9%	68	34.4%	84
Columbia	19.2%	107	33.9%	142
Crawford	21.3%	162	31.8%	182
Cumberland	16.1%	348	32.0%	519
Dauphin	19.3%	412	32.6%	521
Delaware	16.1%	692	29.2%	942
Elk	20.3%	63	31.5%	74
Erie	19.7%	436	37.2%	618
Fayette	23.2%	283	35.1%	321
Forest	25.4%	16	40.6%	19
Franklin	19.4%	268	39.8%	412
Fulton	22.1%	30	36.2%	37
Greene	21.1%	62	36.2%	80
Huntingdon	21.6%	88	36.1%	111
Indiana	20.5%	146	34.0%	182
Jefferson	22.4%	93	38.7%	121

County	Population Percentage Smoking	Increase in Cases from Smoking	Population Percentage Obesity	Increase in Cases from Obesity
Juniata	22.7%	50	35.2%	**58**
Lackawanna	19.2%	374	32.3%	**471**
Lancaster	18.5%	907	33.9%	**1246**
Lawrence	20.4%	180	37.1%	**245**
Lebanon	19.2%	249	36.1%	**351**
Lehigh	18.3%	513	35.2%	**740**
Luzerne	20.2%	584	35.6%	**772**
Lycoming	19.0%	191	34.7%	**262**
McKean	21.3%	76	36.4%	**97**
Mercer	20.4%	234	32.7%	**281**
Mifflin	23.3%	106	35.0%	**119**
Monroe	18.9%	229	32.8%	**298**
Montgomery	13.6%	961	28.0%	**1484**
Montour	18.9%	34	32.5%	**44**
Northampton	17.6%	498	30.6%	**649**
Northumberland	22.0%	193	36.1%	**238**
Perry	21.8%	78	34.5%	**93**
Philadelphia	20.6%	1986	30.6%	**2212**
Pike	18.3%	103	35.7%	**151**
Potter	22.2%	39	36.6%	**49**
Schuylkill	21.4%	282	36.8%	**363**
Snyder	20.8%	78	37.5%	**105**
Somerset	22.1%	170	35.7%	**206**
Sullivan	20.4%	15	34.7%	**19**
Susquehanna	20.8%	81	35.6%	**103**
Tioga	20.6%	83	33.7%	**102**
Union	17.6%	67	33.3%	**95**
Venango	21.9%	113	36.5%	**141**
Warren	20.5%	81	35.3%	**105**
Washington	18.2%	350	32.7%	**471**
Wayne	20.4%	105	32.6%	**126**
Westmoreland	17.6%	639	35.2%	**959**
Wyoming	20.3%	48	35.2%	**62**
York	20.7%	746	33.9%	**916**

Long-Term Care Facilities and Capacities

Pennsylvania has three distinct types of institutional long-term care options: skilled nursing facilities, assisted living residences, and personal care homes. The National Institute on Aging (2023) describes the care available in each facility as well as the funding that supports that care.[20] Skilled nursing facilities provide the highest level of care, while assisted living and personal care help individuals with activities of daily living. In the Commonwealth, skilled nursing facilities are regulated by the Pennsylvania Department of Health while assisted living residences and personal care homes are regulated by the Pennsylvania Department of Human Services.[21]

Each type of facility may have units dedicated to providing specialized care for individuals living with dementia. According to Van Dis (2023), facilities with dementia-specific training and activities are more beneficial for the family and a person living with ADRD than a facility that does not have a dedicated dementia unit. Some benefits of a dementia-specific facility include having specific memory care regulations, staff and other healthcare professionals with specialized dementia training, a secure (locked) facility to keep the residents safe from wandering, and activities geared toward those experiencing ADRD. Facilities without a dedicated memory care unit do not offer these care benefits.[22]

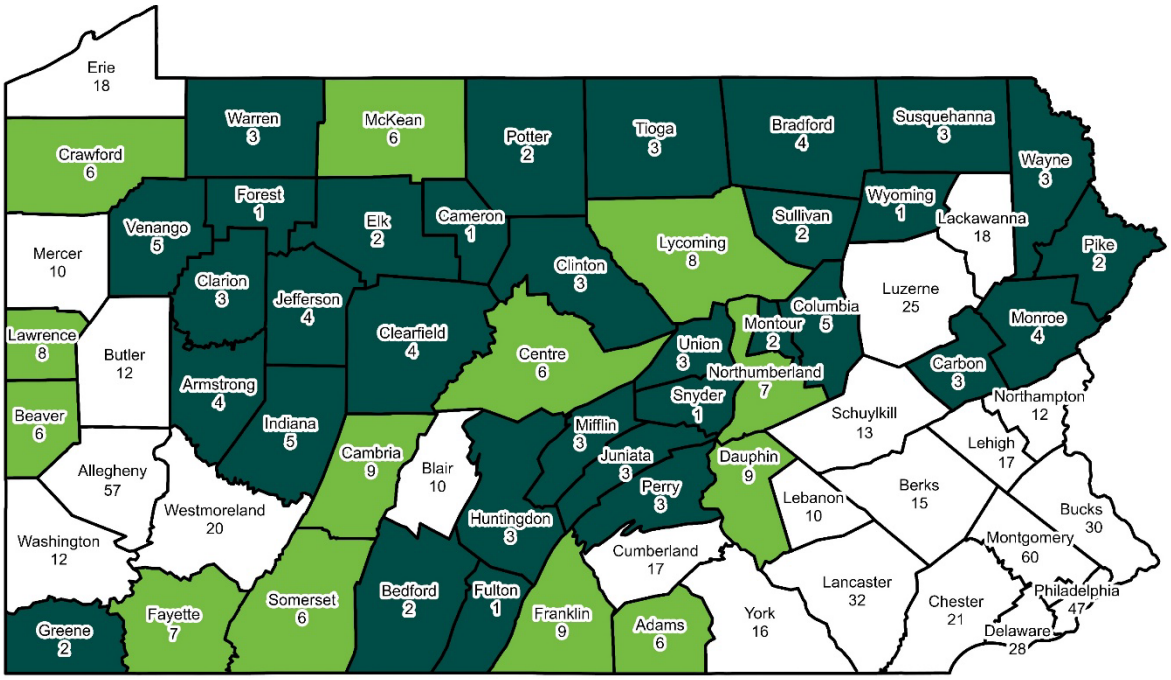
Data from the Pennsylvania Department of Health (2023) show a paucity of facilities equipped to address the needs of individuals living with Alzheimer's disease, according to 2020 data (Figures 1 through 3). Only 488 of 683 skilled nursing facilities within the state have dedicated units for individuals living with dementia, or 71 percent. Approximately one-third of these facilities are in rural counties, but often there is little choice with 23 counties having two or fewer facilities. Urban counties have an average of 17 facilities which have units dedicated to providing specialized care for individuals living with dementia.

[20] See National Institute on Aging (October 12, 2023), "Long-Term Care Facilities: Assisted Living, Nursing Homes, and Other Residential Care," retrieved from Long-Term Care Facilities: Assisted Living, Nursing Homes, and Other Residential Care | National Institute on Aging (nih.gov).

[21] For information regarding licensure and regulations for each type of facility, see the following sources. For skilled nursing facilities, see https://www.health.pa.gov/topics/facilities/nursing%20homes/Pages/Regulations.aspx. For assisted living residences, see https://www.pa.gov/content/dam/copapwp-pagov/en/dhs/documents/licensing/bhsl-licensing/documents/Assisted_Living_Residences-2800_Regulatory_Compliance_Guide_RCG.pdf. For personal care homes, see https://www.pa.gov/content/dam/copapwp-pagov/en/dhs/documents/licensing/bhsl-licensing/documents/Personal_Care_Home-2600_Regulatory_Compliance_Guide_RCG.pdf.

[22] Pennsylvania has additional regulations associated with having a specialized dementia care unit; see sources in the footnote immediately above for these regulations.

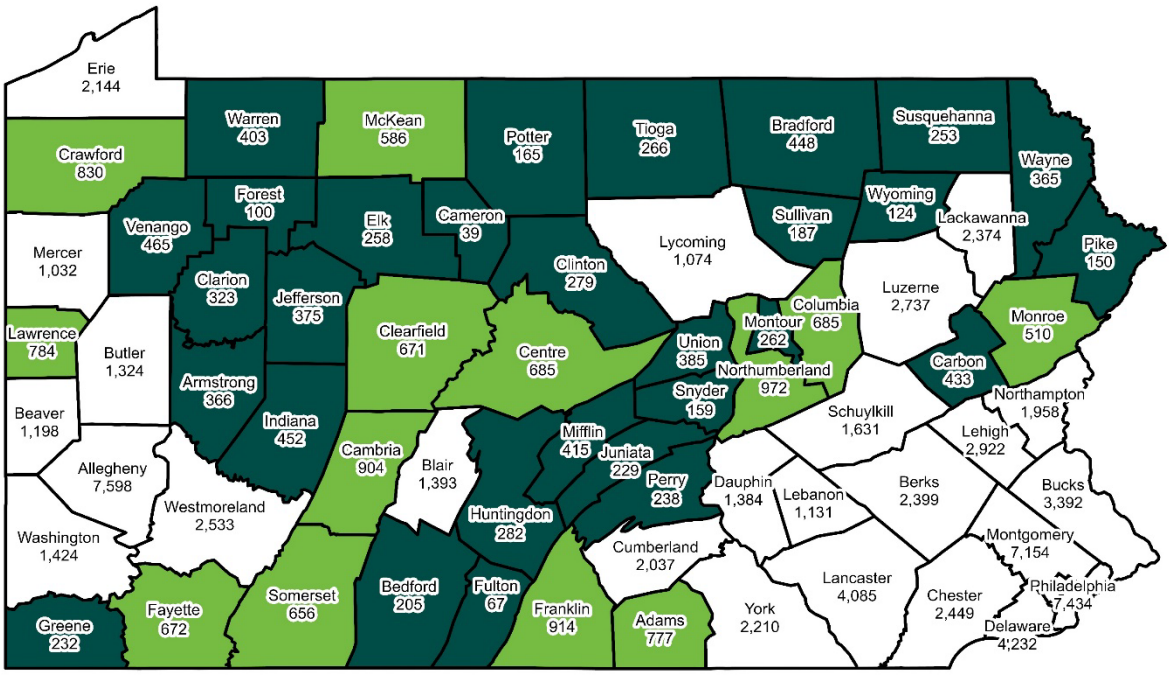
Figure 1: Skilled Nursing Facilities



Statewide Number of Nursing Facilities = 683

- <5 Nursing Facilities
- 5 to 9 Nursing Facilities
- 10+ Nursing Facilities

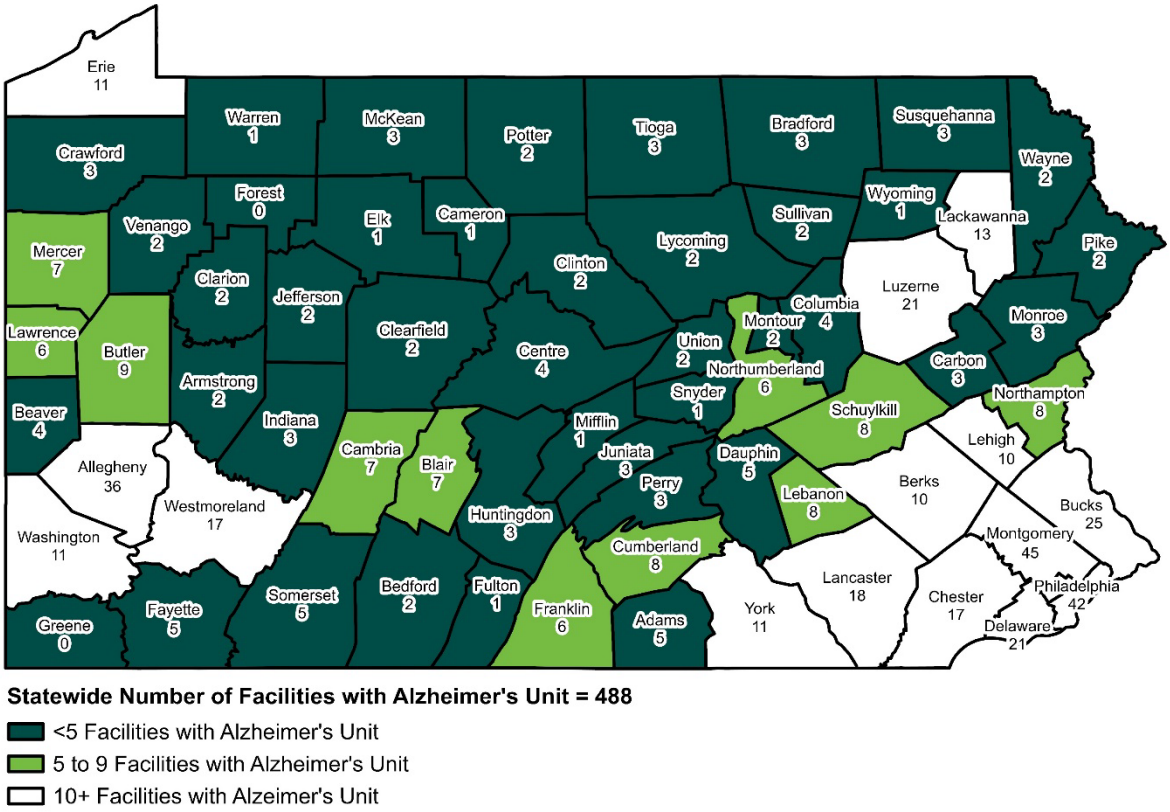
Figure 2: Skilled Nursing Facilities Licensed Beds



Statewide Number of Nursing Facilities Licensed Beds = 86,820

- <500 Licensed Beds
- 500 to 999 Licensed Beds
- 1,000+ Licensed Beds

Figure 3: Skilled Nursing Facilities with Alzheimer's Unit

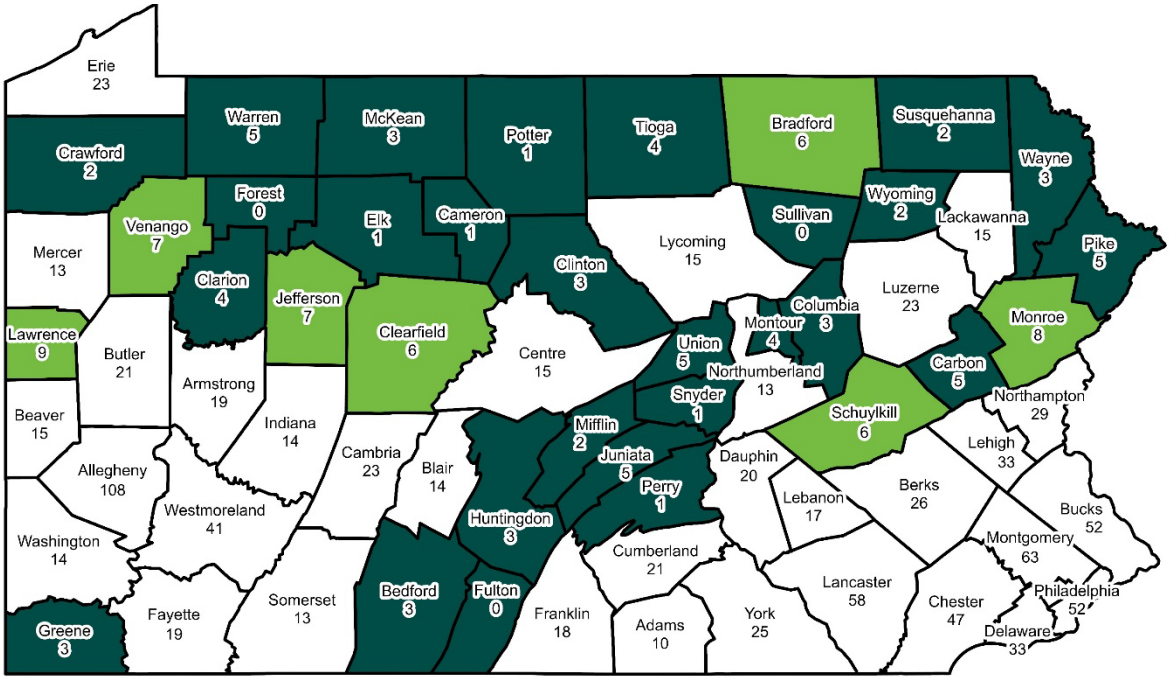


Statewide Number of Facilities with Alzheimer's Unit = 488

- <5 Facilities with Alzheimer's Unit
- 5 to 9 Facilities with Alzheimer's Unit
- 10+ Facilities with Alzeimer's Unit

Beyond skilled nursing facilities, Pennsylvania also licenses special care dementia units at personal care homes and assisted living facilities. Only 328 out of 1,037, or about 32 percent, of personal care homes have beds licensed for special dementia care; 21 rural counties have no facilities with these specialized units (see Figures 4 through 7).

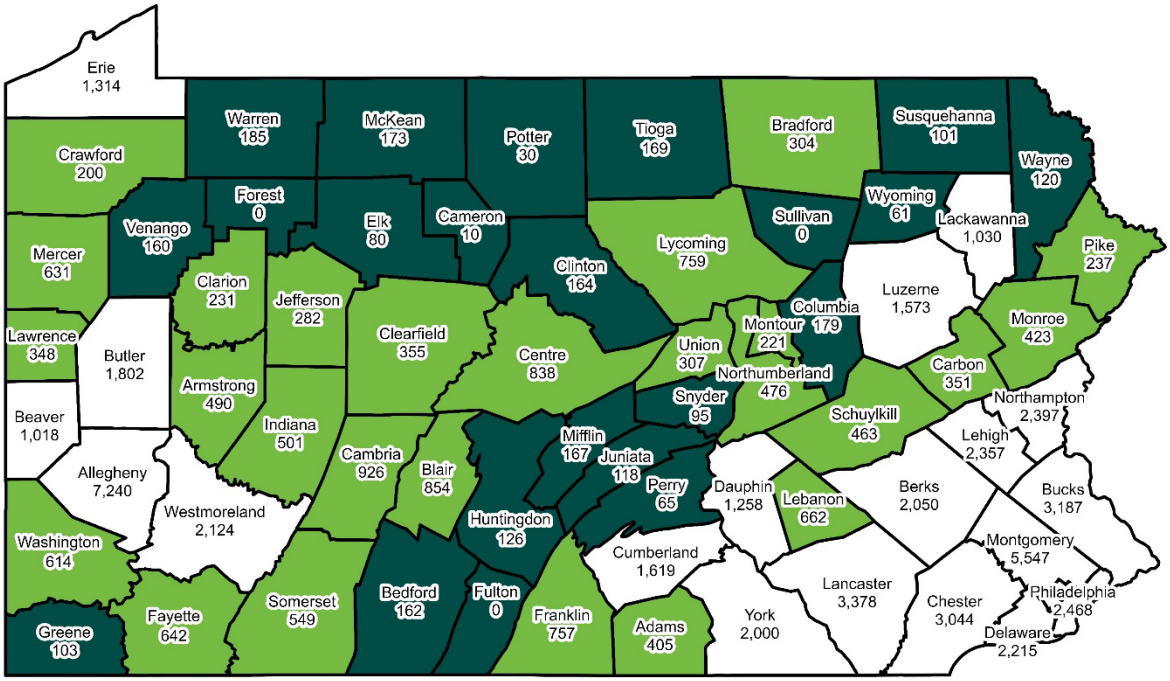
Figure 4: Personal Care Homes



Statewide Number of Personal Care Homes = 1,042

- <5 Personal Care Homes
- 5 to 9 Personal Care Homes
- 10+ Personal Care Homes

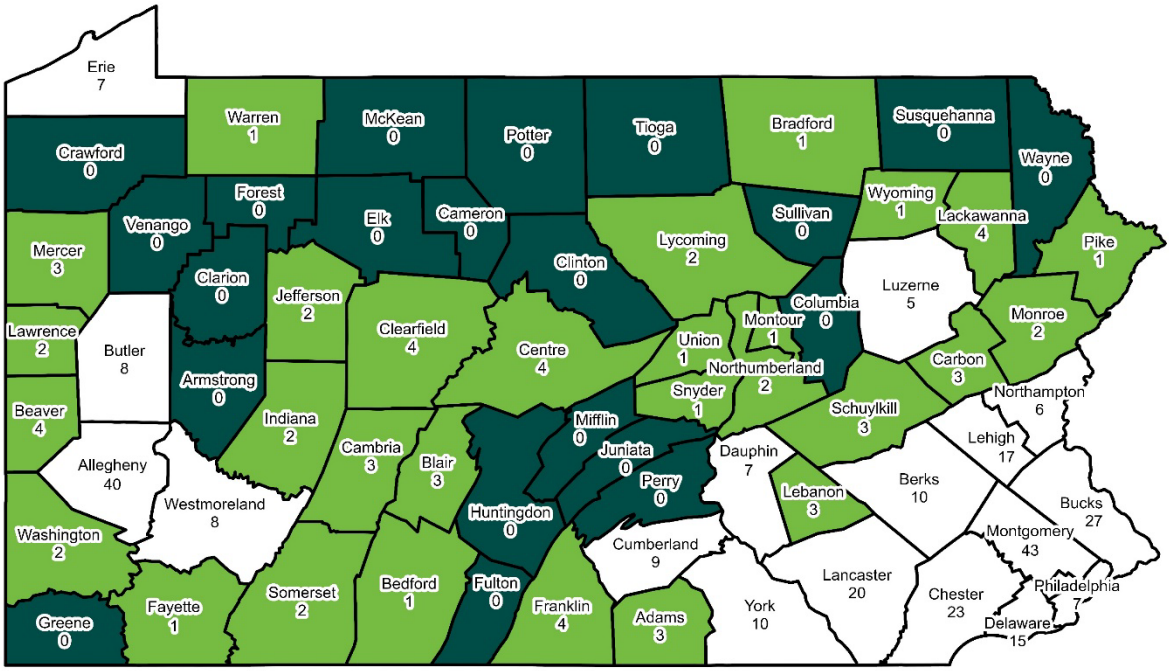
Figure 5: Personal Care Homes Licensed Beds



Statewide Number of Personal Care Homes Licensed Beds = 62,715

- <200 Licensed Beds
- 200 to 999 Licensed Beds
- 1,000+ Licensed Beds

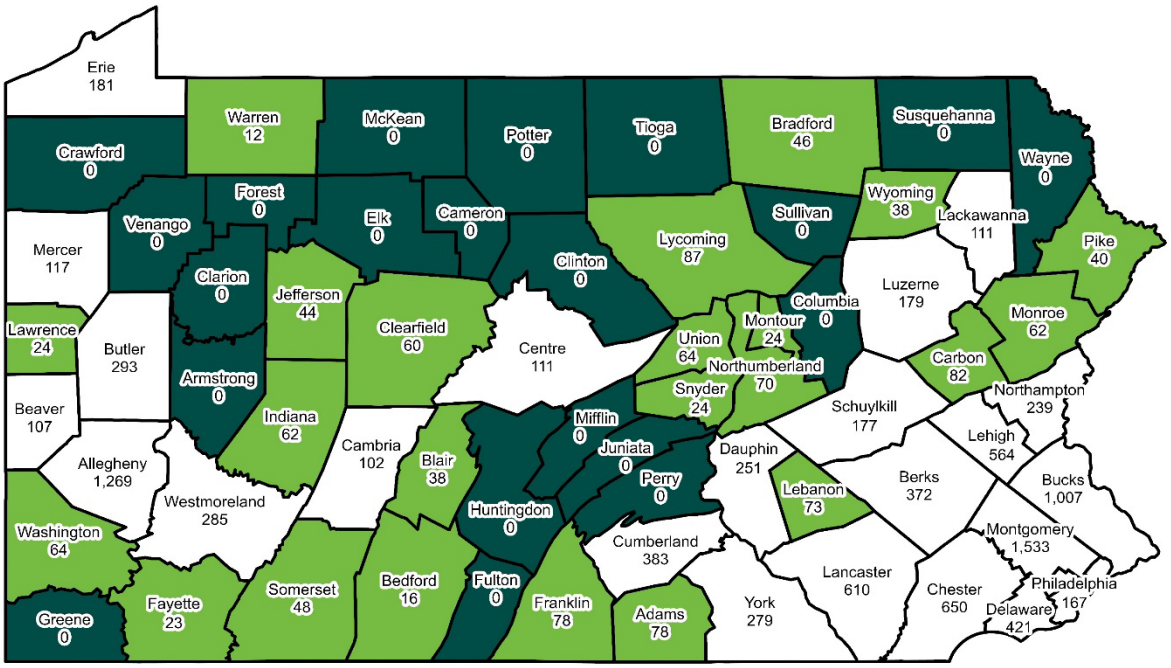
Figure 7: Personal Care Homes with Special Care Dementia Units



Statewide Number of Personal Care Homes with Special Care Dementia Units = 328

- No Special Care Dementia Units
- 1 to 4 with Special Care Dementia Units
- 5+ with Special Care Dementia Units

Figure 6: Personal Care Homes Special Care Dementia Units Capacity

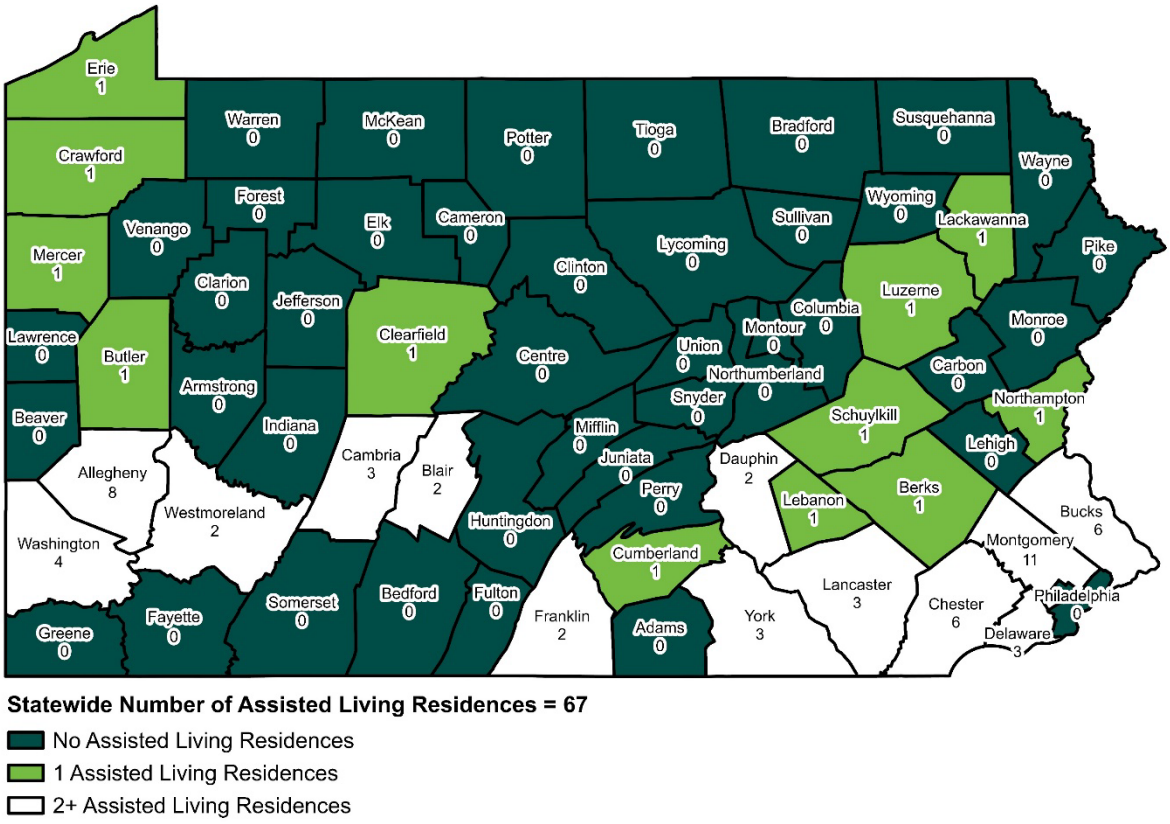


Statewide Capacity of Personal Care Homes with Special Care Dementia Units = 10,565

- No Special Care Dementia Units Capacity
- 1 to 99 Special Care Dementia Units Capacity
- 100+ Special Care Dementia Units Capacity

Of the 66 licensed assisted living facilities, just over half (38) have special care units; 8 of these are in rural counties. Blair, Butler, Cambria, and Clearfield counties have a single facility, while Franklin and Washington counties have 2 (see Figures 8 through 13).

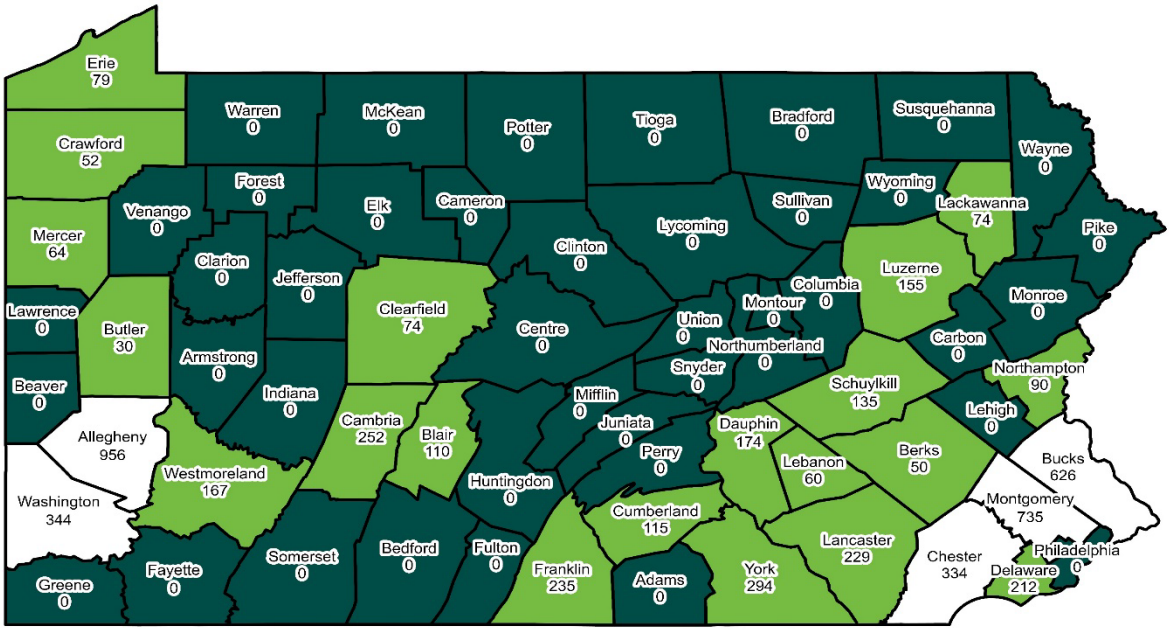
Figure 8: Assisted Living Residences



Statewide Number of Assisted Living Residences = 67

No Assisted Living Residences
1 Assisted Living Residences
2+ Assisted Living Residences

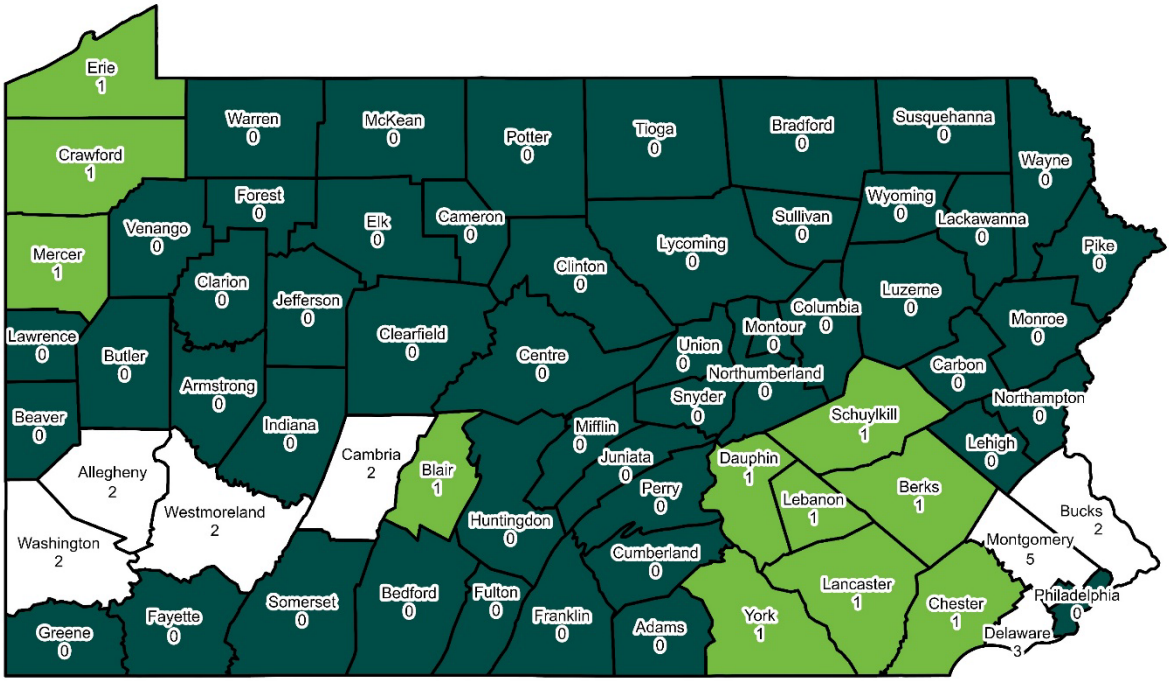
Figure 9: Total Assisted Living Residences Capacity



Statewide Capacity of Assisted Living Residences = 5,646

- No Assisted Living Residences
- 1 to 299 Assisted Living Residences Capacity
- 300+ Assisted Living Residences Capacity

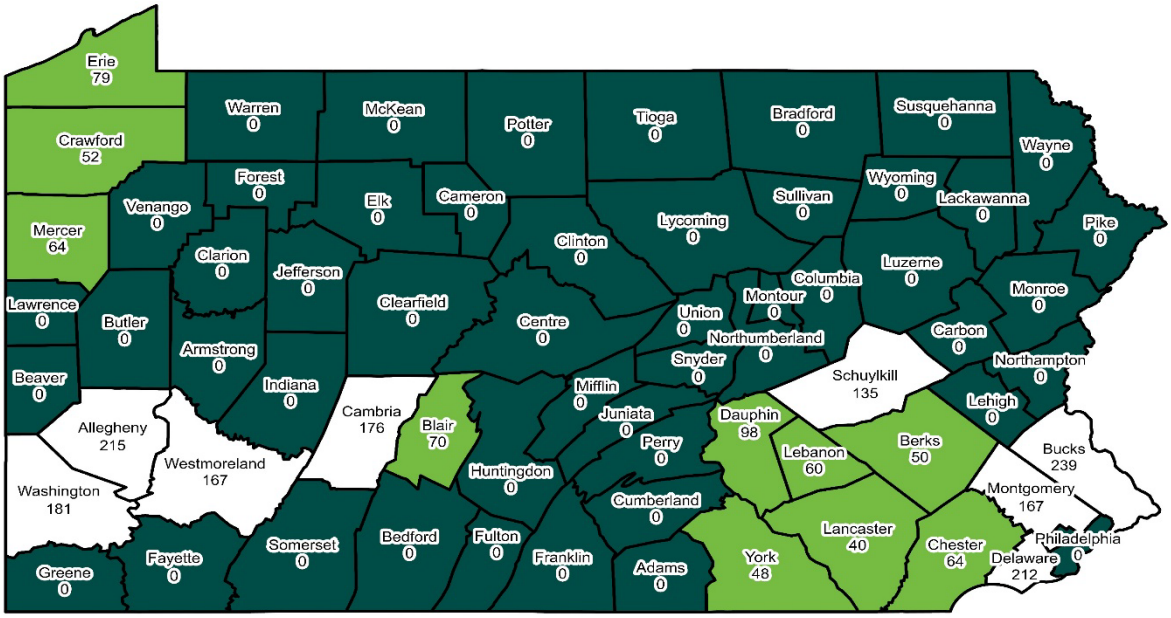
Figure 10: Assisted Living Only



Statewide Number of Assisted Living Only = 29

- No Assisted Living Only
- 1 Assisted Living Only
- 2+ Assisted Living Only

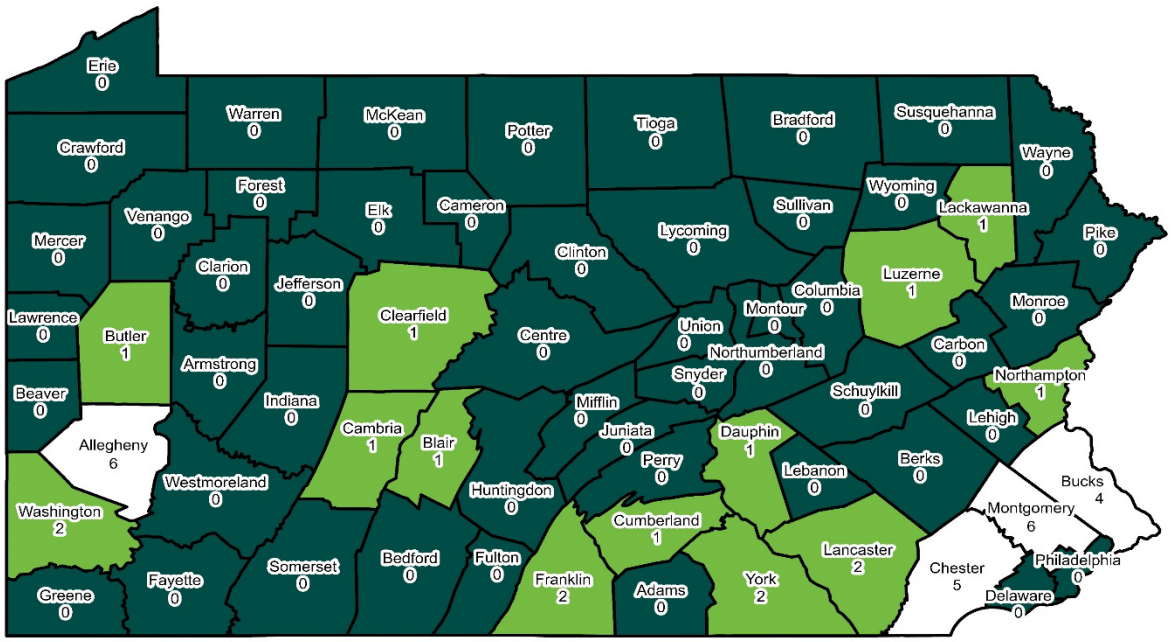
Figure 11: Assisted Living Only Capacity



Statewide Capacity of Assisted Living Only = 2,117

- No Assisted Living Only
- 1 to 99 Assisted Living Only Capacity
- 100+ Assisted Living Only Capacity

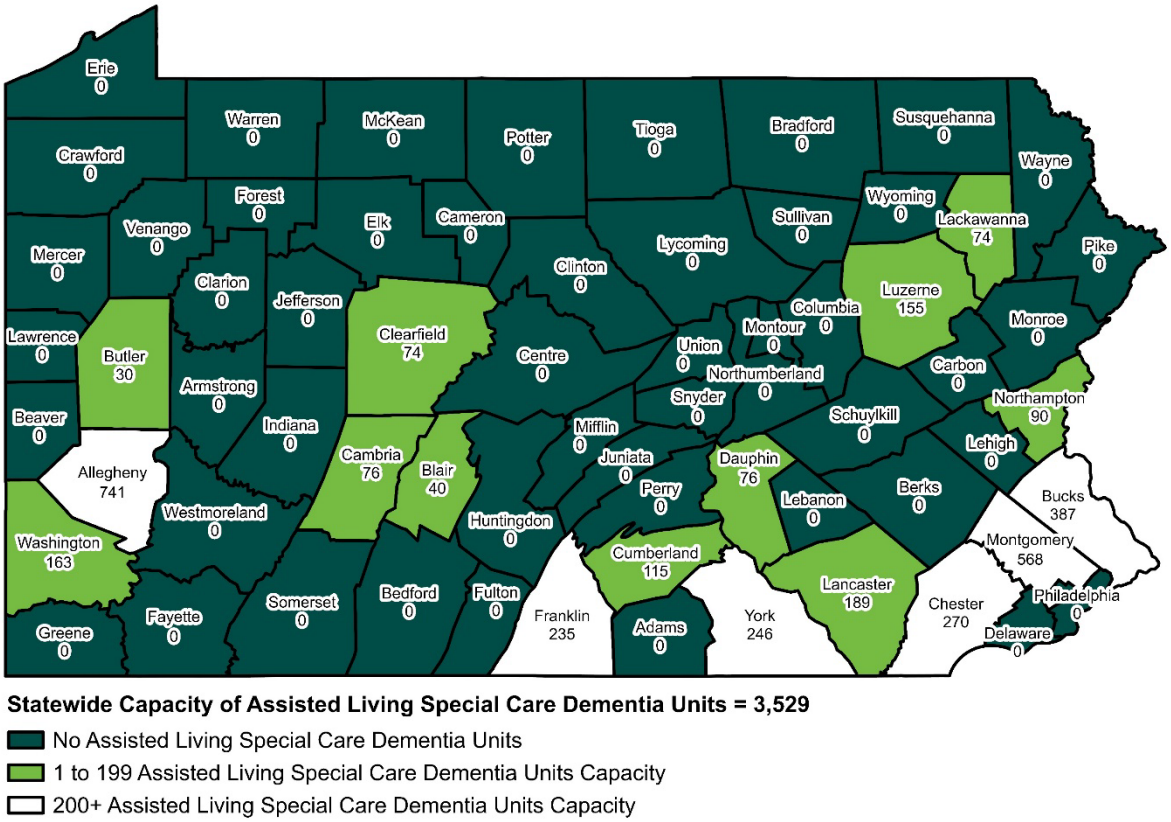
Figure 12: Assisted Living Special Care Dementia Units



Statewide Number of Assisted Living Special Care Dementia Units = 38

- No Assisted Living Special Care Dementia Units
- 1 to 2 Assisted Living Special Care Dementia Units
- 2+ Assisted Living Special Care Dementia Units

Figure 13: Assisted Living Special Care Dementia Units Capacity



Given the shortfall of skilled nursing facilities with Alzheimer's units at present, by 2040, the situation will be compounded with approximately 133,000 more Pennsylvanians living with an ADRD diagnosis.

Even if facilities are available, the question about paying for care becomes paramount. While not intended to be the primary source of an individual's income in older age, Social Security is the major source for most people 65 and older (Dushi and Trenkamp, 2021). Furthermore, the Center on Budget and Policy Priorities (2023) reported that 9.6% of older Pennsylvanians lived below the poverty line ($12,760) in 2020. Table 9 shows the mean Social Security and the mean retirement income in 2021 (in inflation-adjusted dollars, excluding Social Security). Given the median annual cost for a private room ($116,800) or a semi-private room ($108,847) in a skilled nursing facility in Pennsylvania, it is evident 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).

Table 9: Mean Social Security and Retirement Income by County (2020)

County	Mean Social Security (dollars)	Mean Retirement Income (dollars)	County	Mean Social Security (dollars)	Mean Retirement Income (dollars)
Pennsylvania	$21,974	$24,392	**Juniata**	$21,499	$18,888
Adams	$22,471	$28,777	**Lackawanna**	$20,260	$22,193
Allegheny	$21,194	$26,023	**Lancaster**	$23,019	$27,482
Armstrong	$20,736	$20,404	**Lawrence**	$20,825	$18,997
Beaver	$21,555	$21,325	**Lebanon**	$21,198	$22,428
Bedford	$20,028	$23,666	**Lehigh**	$21,785	$25,035
Berks	$21,416	$23,283	**Luzerne**	$19,983	$22,509
Blair	$20,968	$24,449	**Lycoming**	$20,516	$22,281
Bradford	$19,950	$21,082	**McKean**	$19,815	$20,249
Bucks	$24,275	$34,145	**Mercer**	$20,791	$20,724
Butler	$22,408	$26,721	**Mifflin**	$20,738	$19,544
Cambria	$20,044	$18,728	**Monroe**	$22,104	$30,191
Cameron	No data	No data	**Montgomery**	$24,288	$31,609
Carbon	$20,648	$22,228	**Montour**	$20,465	$21,006
Centre	$22,856	$32,531	**Northampton**	$23,071	$26,940
Chester	$24,770	$33,139	**Northumberland**	$19,576	$19,036
Clarion	$20,009	$19,118	**Perry**	$20,796	$27,218
Clearfield	$20,358	$22,003	**Philadelphia**	$17,419	$23,281
Clinton	$19,443	$19,027	**Pike**	$23,403	$28,736
Columbia	$20,163	$23,001	**Potter**	$21,354	$19,449
Crawford	$20,633	$22,755	**Schuylkill**	$20,463	$20,830
Cumberland	$22,379	$31,740	**Snyder**	$21,237	$23,145
Dauphin	$21,452	$27,577	**Somerset**	$20,598	$20,549
Delaware	$22,161	$28,430	**Sullivan**	$20,657	$27,613
Elk	$21,333	$16,307	**Susquehanna**	$20,906	$25,049
Erie	$21,081	$23,696	**Tioga**	$20,816	$23,183
Fayette	$20,273	$20,496	**Union**	$20,641	$34,682
Forest	$20,784	$21,561	**Venango**	$21,387	$20,688
Franklin	$21,604	$29,828	**Warren**	$20,850	$22,322
Fulton	$19,575	$23,637	**Washington**	$22,082	$23,511
Greene	$19,970	$22,961	**Wayne**	$22,120	$25,718
Huntingdon	$20,373	$23,002	**Westmoreland**	$22,021	$25,718
Indiana	$21,372	$25,044	**Wyoming**	$21,227	$23,689
Jefferson	$20,564	$20,632	**York**	$22,202	$24,089

Interviews with Stakeholders

To obtain a comprehensive picture of caring for individuals living with Alzheimer's disease, three groups of stakeholders were interviewed: our partner Area Agencies on Aging, advocacy organizations in the aging network, and family caregivers.

Area Agencies on Aging

To respond to the shortage of services and programs in the United States specifically for adults over the age of 60, the 89th U.S. Congress passed the Older Americans Act (OAA) in 1965. This legislation provided funding for "community planning and social services, research and development projects, and personnel training in the field of aging" (Administration for Community Living, 2023). This law subsequently created the Administration on Aging (AoA), "to administer the newly created grant programs and to serve as the federal focal point on matters concerning older persons" (Id.). The Administration on Aging is housed in the Administration for Community Living (ACL), which is one of 12 agencies operating under the U.S. Department of Health and Human Services and is charged with fulfilling the requirements of the Older American Act.

One of the provisions is to provide funding to state agencies on aging, such as Pennsylvania's Department of Aging (PDA). The PDA was established in 1978 and advocates "for the interests of all older Pennsylvanians, overseeing an array of benefits, services, and programs that are made available through its network of 52 local Area Agencies on Aging (AAAs), which cover the Commonwealth's 67 counties" (Pennsylvania Department of Aging, 2024). Thirty-three AAAs are county-run, while the other 19 AAAs are classified as private, non-profit organizations (see Table 10). The private non-profit organizations may receive funding from the county/counties they serve; however, these non-profits have their own Board of Directors and additional funding streams, such as fundraisers and private donations.

Table 10: Organization of Area Agencies on Aging (*Denotes Counties Which Share Agency on Aging Services)

County	Organization Type	County	Organization Type
Adams	Not For Profit	**Juniata***	Not For Profit
Allegheny	County	**Lackawanna**	County
Armstrong	County	**Lancaster**	County
Beaver	County	**Lawrence**	Not For Profit
Bedford*	County	**Lebanon**	County
Berks	County	**Lehigh**	County
Blair	Not For Profit	**Luzerne***	County
Bradford*	Not For Profit	**Lycoming***	Not For Profit
Bucks	County	**McKean***	Not For Profit
Butler	County	**Mercer**	Not For Profit
Cambria	County	**Mifflin***	Not For Profit
Cameron*	Not For Profit	**Monroe**	County
Carbon	County	**Montgomery**	County
Centre	County	**Montour***	Not For Profit
Chester	County	**Northampton**	County
Clarion	Not For Profit	**Northumberland**	County
Clearfield	Not For	**Perry**	County
Clinton*	Not For Profit	**Philadelphia**	Not For Profit
Columbia*	Not For Profit	**Pike**	County
Crawford	Not For Profit	**Potter**	County
Cumberland	County	**Schuylkill**	County
Dauphin	County	**Snyder***	Not For Profit
Delaware	County	**Somerset**	County
Elk*	Not For Profit	**Sullivan***	Not For Profit
Erie	Not For Profit	**Susquehanna***	Not For Profit
Fayette*	Not For Profit	**Tioga***	Not For Profit
Forest*	Not For Profit	**Union***	Not For Profit
Franklin	County	**Venango**	County
Fulton*	County	**Warren***	Not For Profit
Greene*	Not For Profit	**Washington***	Not For Profit
Huntingdon*	County	**Wayne**	County
Indiana	Not For Profit	**Westmoreland**	County
Jefferson	Not For Profit	**Wyoming***	County
		York	County

To receive services through the AAAs, a person must be over the age of 60, a U.S. citizen or legal resident, and have some sort of need. Examples of programs and services that the AAAs offer include caregiver support, housing, help at home, meals, and prescription assistance (PACE) (see Table 1). Some of these programs funded by the AAAs have income requirements, while some do not (Pennsylvania Department of Aging, 2024).

The researchers interviewed eight individuals who work for a county-level Area Agency on Aging (seven directors and one director of social services; the agencies are listed in Table 2). [23] The interviews covered a wide range of topics, beginning with an assessment of gaps in both formal and informal service provision.

Major themes identified regarding the gaps in service provision for people with ADRD and their caregivers centered around the lack of home care workers, lack of formal services available to help those with ADRD, and the lack of training/education that the direct care workers at the AAA received when they started working (see Table 11).

Table 11: Major Themes from Interviews with Area Agencies on Aging

Top Concern	Percentage Offering the Concern
Lack of Home Care Workers	100%
Lack of Broadband Internet Access	86%
Challenges of Living in a Rural Area	71%
Lack of Formal Services for those with ADRD	43%
Lack of Training AAA Direct Care Workers Receive	43%

Source: Bourassa and Grove, Interview Results of AAA Directors, 2023 (n<10).

All those interviewed believed the foremost issue is the lack of home care workers who provide one-on-one care for the person with ADRD. Home care work is difficult work and notoriously underpaid, and as Director 1 stated, “While caregiving is noble, it is not glamourous work.” A reason for the lack of home care workers was the low level of pay. Directors 4 and 7 noted that some home health care agencies do not reimburse for travel time or mileage from one client’s home to the next client’s home, a financial disadvantage particularly in rural areas. The directors see constant caregiver turnover, which impacts the family and the person with ADRD. Family caregivers need to depend on someone to show up consistently, as it takes time to develop trust and rapport with a new home care worker.

Directors 7 and 8 discussed issues with the 2003 directive regarding contract procurement requirements for the OPTIONS Program, known as “Consumer’s Choice” (Pennsylvania Department of Aging, Aging Program Directive 09-01-03). However, their opinions differed on the reasoning behind this order. AAAs were “required to utilize a competitive procurement system to secure all consumer services…the AAA’s awarded

[23] All rural Directors at the AAAs were contacted; those who volunteered were interviewed. Cumberland County was also included; it has many areas within it that are rural.

each service contract to one provider/vendor or to a very limited number of provider/vendors who were assigned specific geographic regions" (APD, 02-01-03).

The 2003 directive states that AAAs must provide a list of all formal caregiving agencies that the AAA contracts with and allow the consumer to choose the agency that they want to use. The AAA may not have any input in the consumer's decision. However, if a consumer wants a particular agency and there is a waitlist due to lack of staff, the consumer will remain on the waitlist for services from this particular agency, leaving the consumer, and possible family members, without any help. If the AAAs were allowed to offer information about which formal caregiving agencies had the capacity to service their needs, it could enable a consumer to receive services, sooner.

Director 7 asserted if the aging worker could share information with the consumer that a particular agency is providing services to a few of their neighbors, then the consumer may be more likely to receive services quicker because the formal caregiver would not have to drive as far and would be more likely to provide care to another client given their proximity.

Director 8 liked "Consumer's Choice" since it removed the AAA from the decision that the consumer made. This alleviated any sort of "blame" that the consumer might place on the AAA for suggesting a formal caregiving agency if the consumer was not satisfied with the caregiving services. On the other hand, prior to "Consumer's Choice", the AAA could contract with a single home care provider and offer a financial incentive associated with adequate performance and they cannot do so anymore. If the home care agency did not perform, then the AAA could break the contract and find another agency that could provide better services.

Director 8 discussed the challenges that she had with some home care agencies having a minimum set number of hours that they will spend with a person with ADRD. A home assessment with the person with ADRD is conducted by an AAA direct care worker, who decides how many hours of home care the individual needs. The hours of home care are also determined by what the AAA can afford to spend on the individual, as well. Therefore, a home care agency with a minimum of four hours per day would not be able to provide care, if the person with ADRD was evaluated by the AAA direct care worker to qualify for only two to three hours of care a day. The reimbursement rates for home care workers are not sufficient when the number of hours to provide care drives the decision whether or not the home care agency can service the person with ADRD. Consequently, not every person with ADRD who needs care is going to be able to obtain it.

Finally, it can take up to six months for a person with ADRD to be approved for home care services through the OPTIONS Program. Many families give up trying to secure home care services through the AAA because of the wait. Consequently, this leaves many people with ADRD unable to receive home care worker services through the AAAs. The lack of home care workers willing to provide care is driving the long waitlists for the OPTIONS Program. In the past, waitlists were due to the AAAs not having sufficient finances to pay the home care agencies, but now, the waitlists are attributed to having too many people eligible for services, but not enough home care workers at these agencies to provide services. For example, the AAA serving Southwest Pennsylvania has

access to 15 home care agencies. However, the AAA has a waitlist because these home care agencies do not have workers to provide care. Luzerne County has access to more than 20 home care agencies but is also experiencing high wait lists for services due to lack of workers.

Beyond providing home care, Directors 2, 4, and 8 mentioned the lack of adult day center programs in their counties as a problem for the family and person with ADRD. Two directors who oversee multi-county AAAs discussed this problem, with one director stating that there was only a single adult day program available for respite and the other noting that they have not had an adult day care program in either county for the past decade. These directors of AAAs recognize the importance of this formal support and are willing to subsidize the transportation costs. For example, Carbon County AAA pays to transport consumers with ADRD to an adult day center in Schuylkill County.

Director 2 discussed the difficulty of finding appropriate places for someone with ADRD to live. This director stated that several nursing homes in the county have closed entire wings due to a lack of staff to care for older adults, leaving families to handle the caregiving experience alone.

The last major theme identified as a gap in service provision was the discussion surrounding the lack of training and education the directors received at the time of their hire. Six out of eight AAA directors stated that they had deep personal connections with older adults earlier in their lives, which prompted them to work with older adults. Having a strong connection to older loved ones, especially the directors who had loved ones with ADRD, helped them to understand what the caregivers in their counties were experiencing. However, four out of the eight directors indicated that they did not think that they had adequate information and training from the Pennsylvania Department of Aging (PDA) when they started working with caregivers and people with ADRD. Director 4 had to rely on training provided by the Alzheimer's Association, Dementia Friends/Champions, and videos. Two other directors supplemented their training with the same resources and conferred with their peers about aging issues. Directors 2 and 8 did not have any training or education because they started working at the AAA prior to 1987, before mandatory training was a requirement under the Older Adult Protective Services Act.

Currently, the PDA requires all AAA employees to have basic aging training, which is acceptable, but the directors discussed the need for several improvements to the PDA's training modules on the learning management system (LMS). Four of the eight directors want more rigorous trainings that address the different types of dementia, basic information about the dementia disease process, best practices for care, how to have "the conversation" with a person who has ADRD, and trainings about how to better understand and recognize early warning signs that can be related to ADRD. Three of these directors would also like to see the PDA institute required annual training. Currently, the PDA requires the training to be completed upon hiring. However, the typical AAA worker does not have a requirement to continue with yearly training. The majority of these AAA directors actively encourage their workers to participate in additional trainings, which are helpful for the worker, consumer, and family.

In addition to gaps in formal support services, the interviews identified three other themes regarding challenges that limit service provision. The first theme that emerged touched upon broadband internet access issues, which were noted as the major hindrance when caregivers try to obtain information and training about the ADRD diagnosis. Seven directors noted that a major gap in providing education, training, and other services for the caregivers of people with ADRD is due to broadband internet issues. In rural areas, even if a caregiver had internet service, it was often unreliable. The lack of quality internet access is a major hindrance for caregivers seeking additional education and training. Directors 1, 3, and 6 noted that caregivers may not have access to a computer, tablet, or smart phone, and they may not feel comfortable using this type of technology. Increased reliance on automated call centers loses the "personal touch" that may make a caregiver feel more comfortable when calling for assistance.

The next theme centered around the stigmatizing nature of being diagnosed with ADRD. When someone is diagnosed with ADRD, there are many negative connotations that accompany the diagnosis. Directors 3 and 4 discussed the importance of denial of the disease, especially in the early stages, which then causes the family to be reactive in needing information, training, and services, while the family could have been proactive and had all of the necessary information they needed in place when the time came to require more intensive services. This could decrease the feeling that caregivers "are over their heads" and from contacting the AAA when they are in a "crisis" situation. There are very few geriatricians in rural areas, so most of the people with ADRD rely on their family doctor for their healthcare needs. A geriatrician could provide more extensive information about ADRD, due to the specialized nature of the geriatrician's profession. Directors 6 and 8 believed that physicians are not doing enough for the person with ADRD after diagnosis, and the families are then left to find information on their own.

The third theme was difficulty accessing services, such as support groups and in-person information, due to the rural nature of their homes. Living in a rural area can be isolating for the caregiver and the person with ADRD because neighbors do not live close to each other which reinforces their isolation from other informal support systems. To access caregiver support groups, the caregiver may need to drive to their local AAA or to another support group to receive information and training which can be difficult for the caregiver and the person with ADRD. This also can become costly. Director 7 stated that the AAA would pay for transportation to support groups using the Shared Ride program but noted the limitations of such programs which only run during regular business hours, Monday through Friday.[24]

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. It is important to note that the sources of funding for AAAs

[24] As an example of the limitations of the Shared Ride Program, see the information provided by Cumberland County at https://www.rabbittransit.org/wp-content/uploads/2022/12/cumberland-county-travel-guidelines.pdf.

vary considerably across the Commonwealth depending on how the AAA is structured. Some AAAs are funded solely by the federal Aging Services Block Grant, while others receive small contributions in the form of additional finances or in-kind services from their respective counties. Of the counties that served as partners for this project, only three received additional funds or in-kind services from the counties they served (Columbia-Montour, Luzerne-Wyoming, and the Southwestern Pennsylvania Area Agency on Aging).[25]

In addition to gaps and challenges, the interviews with directors also pointed to the importance of collaboration and establishing solid partnerships with various agencies and programs. The Alzheimer's Association was mentioned the most often as an agency that the directors utilized for accessing services, information, and/or education. Another program that three of the eight directors utilized for training is Dementia Friends-Pennsylvania. Partnerships with local health care facilities, including hospitals, nursing homes, local continuing care retirement communities, home care, and hospice agencies were used by five of the seven AAAs interviewed. These partnerships took the form of Caregiver Health Fairs and Health and Wellness Nights where community members learn more about ADRD and caregiving issues.

Two AAAs collaborated closely with county-based social services, local social service agencies and clubs in their county, such as the Carbon County Collaborative Board, LINK in Cumberland County, Cumberland County Housing and Development Authority, homeless shelters, and the Lion's Club. Lastly, one county had various partnerships with private companies, such as a pet food company which provided pet food coupons to keep consumers from sharing their meals with their pets, veterinary services for homebound elderly, and a medical supply company which provided uncovered incidentals for those with Medicare. This county also partnered with the pre-med students at their local college who worked in the community care network to help those older adults who often frequented the healthcare system.

To conclude the interviews, the directors were asked, "If finances were endless, what types of programs and/or services would you like to see created to help caregivers and those with ADRD?" Four major themes emerged from the responses: 1) the ways the AAA can provide more assistance to informal caregivers; 2) policy changes to improve services for informal caregivers and people with ADRD; 3) state-level policy and program changes; and 4) the means to strengthen connections to the medical community and other audiences.

The directors recognized a variety of areas where the AAA could provide more assistance to individuals living with a dementia-related diagnosis and their caregivers. Recognizing the challenges of being located in a rural area, providing more and

[25] The AAA serving Luzerne (urban) and Wyoming (rural) does not receive any additional funding from Luzerne County, while Wyoming county provides some financial assistance. The AAA serving Columbia and Montour counties receives funding from each county. Two of the three counties served by the Southwestern Pennsylvania AAA do not contribute any extra funding.

improved transportation services was a goal for one AAA. Providing more meals to seniors was another goal, with Director 1 recognizing that malnutrition was a major issue for in their county. Paying for respite care (even if the person with ADRD does not qualify for the OPTIONS Program) and assisting with the planning of it were discussed, with Director 3 suggesting a concierge-like approach and Director 8 suggesting an educational retreat that included both the individual living with ADRD and the caregiver to learn strategies for addressing the disease. Director 7 wished for additional funding for the Elder Cottage Housing Opportunity (ECHO) program. This program provides resources for the construction of a small home for the individual living with ADRD located on the property of the caregiver. Finally, having music and art therapy programs for individuals with ADRD were goals for Director 7 and 8.[26]

When considering policy changes, paying home care workers higher salaries is of utmost importance as is improving training. Providing additional support for home care workers could help decrease the incidences of quick turnovers that plague this valuable profession. Home care workers often could benefit from some of the same programs that their clients are using (i.e., Medicaid, SNAP, food banks), but they may not be aware of their eligibility or even what services are available and may benefit from coaching or assistance in finding the resources. Overall, there is a crucial need to "help the helper."

Additional comments associated with policy changes emphasized one theme discussed previously — improved access to broadband internet service, and four additional areas: expansion of adult day services, modifications to long-term care insurance policies focusing on in-home care, changes to the OPTIONS Program, and a clarification about the Shared Ride Program. As seen in Table 12, the number of adult day programs is low in rural counties; even if there is a program, the hours may not be long enough for individuals who have longer commutes to their homes.

[26] For a discussion of music therapy, see Bleibel, et al. (2023), "The effect of music therapy on cognitive functions in patients with Alzheimer's disease: A systematic review of randomized controlled trials," *Alzheimer's Research & Therapy*, 15, 65: https://doi.org/10.1186/s13195-023-01214-9. The efficacy of art therapy is discussed by Emblad and Mukaetova-Ladinska (2021), "Creative Art Therapy as a Non-Pharmacological Intervention for Dementia: A Systematic Review," *Journal of Alzheimer's Disease Reports* 5(1): 353-364. https://doi.org/10.3233/ADR-201002.

Table 12: Number of Adult Day Centers by County (2024)

Conty	2024	County	2024
Pennsylvania	227	**Juniata**	1
Adams	1	**Lackawanna**	4
Allegheny	24	**Lancaster**	6
Armstrong	2	**Lawrence**	1
Beaver	5	**Lebanon**	1
Bedford	1	**Lehigh**	2
Berks	3	**Luzerne**	6
Blair	4	**Lycoming**	1
Bradford	1	**McKean**	0
Bucks	18	**Mercer**	3
Butler	6	**Mifflin**	2
Cambria	2	**Monroe**	0
Cameron	0	**Montgomery**	15
Carbon	1	**Montour**	0
Centre	1	**Northampton**	4
Chester	4	**Northumberland**	2
Clarion	2	**Perry**	0
Clearfield	1	**Philadelphia**	46
Clinton	1	**Pike**	0
Columbia	1	**Potter**	1
Crawford	0	**Schuylkill**	4
Cumberland	2	**Snyder**	0
Dauphin	3	**Somerset**	2
Delaware	12	**Sullivan**	0
Elk	2	**Susquehanna**	0
Erie	9	**Tioga**	1
Fayette	0	**Union**	0
Forest	0	**Venango**	2
Franklin	1	**Warren**	0
Fulton	0	**Washington**	4
Greene	0	**Wayne**	1
Huntingdon	2	**Westmoreland**	5
Indiana	1	**Wyoming**	0
Jefferson	1	**York**	2

Having a "drop-in adult day center" with less paperwork could help caregivers who need a short-term, last-minute option. While some long-term care insurance policies offer respite care as part of their benefits, Directors 1 and 6 noted that it is difficult to navigate the "red tape" associated with finding a placement and being reimbursed. Two directors wished that their OPTIONS Program could provide more hours for home care workers to help care for the person with ADRD. Finally, the definition of "essential trips" needs to be clarified and expanded to include transportation for caregivers to attend caregiver training.

The creation of the "Wish List" involved discussions of the relationships between individuals living with dementia, their caregivers, and the medical community. Increasing the numbers of geriatricians, dialysis centers, medical centers, and hospitals is critical for this set of stakeholders. Caregivers struggle with transporting individuals with ADRD to medical facilities and one wish was for the return of the "house call." Facilities and medical professionals who specialize in the treatment of Alzheimer's disease and related disorders are predominantly located in the Commonwealth's urban centers (i.e., the University of Pennsylvania's Alzheimer's Disease Research Center and the University of Pittsburgh Alzheimer's Disease Research Center). Having satellite centers was recommended by one AAA director.

Directors 2, 5, 6, and 8 suggested implementing a transition coach or care manager position in physicians' offices for practices that have served high numbers of older adults. The transition coach would help people with a new ADRD diagnosis, and their caregivers deal with adjustment issues and serve as a "warm handoff."[27] The practicality of adding these positions could be addressed with the creation of a central call-in center, where physicians could send referrals for those newly diagnosed with ADRD.

Beyond the medical community, outreach to the public in general is needed to address the stigma associated with ADRD and to promote the need for more caregivers in the coming decades. Director 2 established connections with a local college's pre-med program. Students learn about issues facing older adults and how to recognize and help those who are struggling; the students then serve as a "community-care network" and help individuals who may have been sent home from a facility without adequate preparation. Establishing programs in local high schools to teach the students about ADRD may dispel some of the stigma associated with the disease and stimulate interest in working with this population in the future.

[27] The concept of a "warm handoff" appears in the medical literature in a variety of contexts, including primary care settings (Sanderson, et al., 2021), treatment for opioid overdoses (Pennsylvania Department of Drug and Alcohol Programs, 2024), and mental health treatment (Fountaine, Iyar, and Lutes (2023)). The idea is explored in the concept piece by the Agency for Healthcare Research and Quality (2017) found at: https://www.ahrq.gov/patient-safety/reports/engage/interventions/warmhandoff.html.

Advocacy Organizations

While the directors of our partner AAAs provided information about their programs and services, the researchers determined that additional stakeholders from the advocacy community should be interviewed to provide a more complete picture of the challenges, present and future, to providing care to individuals living with a dementia-related diagnosis and their caregivers. Recognizing that no single list of organizational stakeholders exists, the researchers opted for a convenience sample, recruiting individuals for interviews through contacts with the Area Agencies on Aging, the Pennsylvania Association of Area Agencies on Aging (P4A), and personal contacts made through Shippensburg University's Gerontology Program. A list of the stakeholders and their respective organizations is included in Appendix 3.

These interviews focused on the gaps in serving individuals living with dementia and their caregivers. Major themes related to the work force (labor shortages and low wages),[28] the negative perception of home care workers, and additional training needs emerged from this set of interviews. These themes are similar to the themes discussed by the Directors of the AAAs (see Table 13).

Table 13: Top Concerns from Interviews with Organizational Stakeholders (Advocacy Organizations)

Top Concern	Percentage Offering the Concern
Lack of Home Care Workers	71%
Low Wages of Home Care Workers	43%
Lack of Training for Home Care Workers	36%
Home Care Workers and Transportation Issues	29%
Negative Perception of Home Care Workers	14%

Source: Bourassa and Grove, Interview Results of Advocacy Organizational Stakeholders, 2023 (N = 14).

Ten out of fourteen stakeholders mentioned the lack of people interested in working as home care workers as the major problem that they confront in trying to provide care. Interviews provided insights about why it may be difficult to recruit the best trained individuals for these jobs. One possible barrier to recruitment are the requirements for hiring. Pennsylvania requires home care candidates to participate in a face-to-face interview with prospective agencies (see 28 Pa.C.S. § 611.51 relating to hiring or rostering of direct care workers). During the COVID-19 pandemic, the Pennsylvania Department of Health waived this requirement and permitted home care agencies to interview candidates online. As of September 2021, the use of online interviews was discontinued.[29] Stakeholder 8 shared their perspective, "You are dealing with lower income, mostly minority women, single mothers for the most part, who have

[28] A third area of concern was the negative image of home health care workers. This has been omitted due to space limitations.

[29] See the recommendation regarding this regulation at https://www.legis.state.pa.us/WU01/LI/TR/Transcripts/2021_0138_0004_TSTMNY.pdf .

finite resources and finite time in their schedules". This stakeholder thought that it was impractical for a potential home care worker to take time off during their day to participate in an in-person interview. The home care worker may have to utilize various forms of transportation (buses, trains, other forms of public transportation) to arrive at the home care agency. Stakeholder 8 continues, "It is not simple...I think some of us might take it [transportation to an interview] for granted. This is a great way to interface with someone before they come in for their training and it also helps to expediate the onboarding process."

Transportation requirements of the job itself inhibit the efforts to recruit people to work as home care workers in rural areas, as well. Stakeholder 9 thought that driving was an issue, especially in rural areas. Workers "are not willing to drive more than thirty minutes to get to a client. It doesn't make financial sense for them." A home care worker in a suburban area can make eight visits a day, while someone in a rural area can only make four visits, due to the driving distances. Home care workers are often not reimbursed for their travel time, only the time that they spend with the person needing care. Therefore, a worker who can visit many consumers in a day in close vicinity would make more money than a rural care worker. This is compounded by the limitations on the number of hours associated with supporting a specific activity of daily living. For example, if an individual living with dementia needs assistance with bathing, the hours are divided throughout the week. In most cases, two hours for a bath are not necessary; however, it is challenging for home care agencies to provide staff for a small, one-hour increment.

Six out of fourteen stakeholders stated that direct care workers are not paid well, and this directly impacts the willingness of someone to work as a home care worker. As mentioned by the AAA directors, the average pay for a home care worker in Pennsylvania is $13.35 per hour, while the average wage for a hand laborer in a Pennsylvania distribution warehouse is $18.70 per hour (Bureau of Labor Statistics 2022). Caregiving is a much-needed service. However, due to low reimbursement rates from Medicare and Medicaid, home care agencies cannot afford to pay their home care workers more. The Pennsylvania Homecare Association (n.d.) states that, "Current Medicaid reimbursement for homecare agencies ranges from $17.52 to $19.52 per hour, depending on the geographic location of the agency."[30] Furthermore, Stakeholder 1 noted that it has been a long time "since we've had an infusion of funds in the OPTIONS Program...this is the first governor that's paying attention to this in a very long time".

A home care worker must meet the training program requirements as outlined by the Centers for Medicare and Medicaid Services. These requirements include "classroom and supervised practical training that must total at least 75 hours. Moreover, a minimum of 16 hours of classroom training must precede a minimum of 16 hours of supervised practical training as part of the 75 hours" (TruCare Home Care Services, 2022). When

[30] This issue was noted by stakeholders working in long-term care settings as well. An agency or long-term care facility can charge the consumer more if the person who receives care is paying privately.

the seventy-five hours of training are completed, home care workers do not need to complete any additional training. Four respondents believed that home care workers would benefit greatly from additional consumer care training and knowledge about ADRD. Respondents noted that some workers are ill-equipped to handle behavioral issues, and no training is required to learn about ADRD. The lack of reimbursement for additional training for home care workers contributes to this gap. As Stakeholder 9 noted "We don't have the training capacity to really help these caregivers be fully prepared to walk into these situations. The stakeholder's company will pay for the initial training of new caregivers, but the company does not get reimbursed for providing this training to the new workers and "that's a cost that comes directly out of our non-billable resources."

If home care workers are only trained in the basics of providing care to a person in their home environment, the aide may not be prepared to deal with the complexity of ADRD nor the behaviors that are associated with people who have dementia. Coupled with the fact that home care workers have historically been paid low wages, have difficulty with transportation (especially in rural areas), and are in a profession that is not seen as valuable as other medical professions, the advocacy organizations believe that Pennsylvania will continue to see a dearth of people wanting to be employed in this field.

The interviews with the advocacy organizations focused on their "wish lists" to help individuals living with ADRD and their caregivers. Their responses focused on programs or services for informal caregivers (financial assistance, education and training, and caregiver support programs) as well as programs or services for home care workers.

Advocacy organization stakeholders agreed there needs to be more money allocated to help keep people with ADRD aging in place. Keeping individuals living with Alzheimer's disease in their homes would also be facilitated by allowing spouses and individuals holding a power of attorney (POA) to be eligible to be paid caregivers through the Community HealthChoices Program. If a spouse or a POA would be eligible to be paid as a caregiver, this could ameliorate issues related to a person who may have to stop working to care for the person with ADRD or being able to find formal home care aide services or long-term care facilities in geographically remote areas, described by Stakeholder 6, as "dementia deserts."

Respondents who worked for advocacy organizations see benefits from educating informal caregivers and the public in general. Having "hands-on-training from Day 1 for the caregivers...similar to what staff members receive in facilities and keep your loved one at home for as long as possible, I think that would be huge" (Stakeholder 2). This would also be extremely helpful among minority cultures, due to the desire for communities of color wanting to take care of their family members at home. Three respondents spoke about the importance of education in detecting the signs and symptoms of dementia. If families can detect the initial signs of dementia, then the person with ADRD would be able to get treatment and a plan of care in place much

earlier as well.

Respondents shared ideas for additional respite programs to help informal caregivers. The lack of adult day care facilities, especially in rural areas, was discussed. Caregivers need a safe space to be able to drop off their loved ones for a few hours, in case of an emergent need or if the caregiver would like to participate in some respite for themselves. Additional funding needs to be provided to reimburse the caregivers for the use of adult day centers. According to SeniorCare.com (2024), the average monthly cost for someone to attend adult day care is $1,300 a month.[31] If the caregiver receives and uses the entirety of their maximum support allowance ($600 a month), then the caregiver still needs to find $700 to pay the balance.

Roughly a third (five of fourteen) of stakeholders also discussed programs and services that could benefit the home care workers who care for individuals living with an ADRD diagnosis. Three ideas emerged: increasing interest in and compensation for working as a caregiver, establishing incentive programs, and providing additional training, education, and support programs. Stakeholder 6 suggested introducing younger Pennsylvanians to careers in caregiving, specifically in middle school, "We're looking at the careers that are going to be here for the next five to ten to fifteen to twenty years and [there is] no more apparent need than in long-term care. So, if we're talking to younger Pennsylvanians now about careers...talk about these types of careers because they are going to be around for years." To attract new individuals to caregiving, it is clear that a higher wage is needed. Stakeholders provided ideas for incentive programs beyond wages. Noting that a majority of home care workers are women, and many are single mothers, one advocate suggested tax credits for transportation or childcare. Creating programs to help finance enhanced education (such as certifications or licensure for CNA) may entice individuals to enter this field.[32] Improving training, specifically for caring for individuals living with Alzheimer's disease, could include funding to attend workshops and conferences, in addition to paid wages during training. Finally, Stakeholder 9 suggested the creation of virtual caregiver support group programs for home care workers to share their struggles with other workers and offer support to one another.

[31] On average, individuals participate in activities at adult day centers two to three days per week for up to five hours per day. See Weissert, et al., (1990), *Adult day care: Findings from a national survey*. Baltimore, Maryland: Johns Hopkins University Press.

[32] In a similar vein, loan repayment programs exist for primary care medical, dental, or mental and behavioral health workers providing services to pre-identified communities in need through the National Health Service Corps (see https://nhsc.hrsa.gov/loan-repayment/nhsc-loan-repayment-program). However, there does not appear to be any repayment programs or financial incentive programs that are geared specifically toward geriatricians or home care workers.

Family Caregivers

In addition to formally trained caregivers who are employed to care for those with dementia, we know that many individuals provide informal care to those diagnosed, particularly family members. According to the Pennsylvania Chapter of the Alzheimer's Association (2022), the value of unpaid caregiving was approximately $10.04 billion with the total time caregivers spent in unpaid care equal to 642 million hours. As Caregiver 7 told us:

> Family caregivers are the backbone of the long-term care system. And if you don't take care of the caregivers, you're gonna have a long care term system that will be bankrupt because there's no way that the state or the counties could provide assets to help people...But they also need to focus on giving help for that caregiver.

For this project, the research team interviewed 12 family caregivers who represented a cross-section of the caregiving community (see Table 14 for a description of the caregivers and the care recipients).[33] The interviews followed the semi-structured guide found in Appendix 1. Table 15 provides a summary of the challenges discussed by the family caregivers during the interviews.

[33] The research team worked throughout the last nine months of this project to recruit additional family caregivers for interviews. This included a call for participants by AAA directors, support groups, a Montessori website, and some home care agencies. Other efforts included working with county partners to identify prospective caregivers, attending support groups, visiting senior centers, and communicating with individuals working in the aging network. While the number of respondents appears low, it is in line with the study by Kiliç, et al., (2023), "Perspectives of Family Caregivers of People with Alzheimer's Disease on Caregiving Experience and Needs: A Qualitative Study," *Journal of Psychosocial Nursing and Mental Health Services*, 13:1-10. doi: 10.3928/02793695-20231106-01. This study had a sample of twenty-three caregivers.

Table 14: Description of Family Caregivers and Individual Receiving Care

Respondent Number	Caregiver	Individual Receiving Care	County
1	Husband	Wife	Schuylkill
2	Son	Father, who lives in a secure memory care unit	Luzerne
3	Daughter (and Son-in-Law)	Mother	Washington
4	Wife	Husband	Columbia
5	Daughter	Parents (father now deceased; mother who has mid-stage dementia)	Washington
6	Daughter	Mother, who lives next door in a separate house	Fayette
7	Niece by marriage	Husband's aunt, who lives in a nursing home	Cumberland
8	Husband	Wife	Cumberland
9	Niece	Aunt, who lives in an independent apartment	Franklin
10	Daughter / Wife	Parents in their 90s and husband in his 70s	Montour
11	Wife / Daughter	Wife, who has MS and memory loss; cared for mother with her brother	Franklin
12	Daughter	Parents	Franklin

Table 15: Major Challenges from Interviews with Family Caregivers

Top Challenge	Percentage Offering the Challenge
Caring for Themselves	92%
Major Changes in Personal Lives	83%
Alterations in Living Arrangements	50%
Loss of Prior Retirement Plans	33%
Finding ADRD Caregiving Resources	33%

Source: Bourassa and Grove, Interview Results of Family Caregivers, 2023 (N = 12).

To begin the interview, the family caregivers were asked about the changes that they had to make in their lives when they started providing care for their family member or friend who is living with a dementia-related diagnosis. Three major themes identified by the caregivers were: work/employment changes, personal changes, and the loss of the "retirement dream."

By far, the biggest adjustments or changes in the informal caregivers' lives involved changes to their prior employment. Out of the 12 responses in this category, one-third had to either quit their jobs or drastically scale back the hours that they could work to provide care for their loved one.

Caregiver 10 stated that she had just secured her "dream job" and was working there for one year, before she had to quit the job to care for her parents. She then had to take on two work-from-home jobs, to try to make up for that lost income. However, these two jobs did not provide her with the same level of income. Caregiver 7 worked out of her home, as a hair stylist. She had to modify the number of hours that she could work and installed multiple cameras around the home, so she could still provide her services, while being able to watch her husband. This resulted in a loss of income, which was sorely needed since her husband had to retire early due to his chronic illness, ultimately impacting the amount of money that he received from Social Security.[34] Caregiver 3 used to operate a daycare center for infants and children out of her home. She had to close the daycare center to care for her mother. Luckily, Caregiver 3's spouse is still employed teaching music at the public school. He used to offer private music lessons in their home, which helped in securing additional income. Because of COVID-19 and Caregiver 3's mother moving in with them, he is not able to offer as many private music lessons as before.

Three additional respondents (Caregivers 5, 6, and 11) retired earlier than expected in order to care for their family members. All respondents mentioned that they would still have kept working if they did not have to care for their loved one. The impact of earlier-than-anticipated retirement may have negative financial consequences for caregivers. Caregiver 6 stated that she lost $600 a month in future Social Security payments, due to retiring at age 62 to care for her mother.

Only two respondents were still working full-time while caring for their loved ones. Caregiver 9 was working as an agency home care worker when her aunt needed care. Caregiver 9 was hired by her aunt's health care attorney-in-fact to provide home care services under the Community HealthChoices Program.

In addition to changes in employment, most respondents (10 out of 12) discussed three categories of changes that affected their personal lives when they started caring for their loved ones: lifestyle adjustments, alterations in their living environments, and loss of retirement plans.

The need to adjust lifestyle most often included a loss of personal time/freedom,

[34] While Respondent 7 left her employment to care for her husband, he did not have a dementia-related diagnosis. Respondent 7 also cared for her parents, who did have a dementia diagnosis.

changes in friendships, or an inability to attend their chosen house of worship. The loss of personal time and lack of freedom was mentioned by six respondents mentioned as the biggest change in their lives. Caregiver 7 stated that she could not leave her home when caring for her husband for 9.5 years and only took 2 days “off” during this time. She felt that she “gave up [her] life.” Caregiver 1 told us: “My time is not my time anymore. And any free time that I get, I'm catching up with bills or doing research online or reading some of the books [on dementia] that I got. It's taken over my life. There's no doubt about that, and it is what it is. So, you know, I'm just trying to make the best of it.”

Pertaining to the element of changes in friendships, five caregivers discussed that they have lost many friendships or are not able to spend as much time with their friends as they used to before caregiving. Caregiver 4 and her husband moved from their urban lifestyle to their rural home 10 years ago. Prior to her husband developing ADRD, she would be able to easily visit her friends in the city, and she did not have a real need to make any friends in her new area. This has now caused feelings of isolation for the caregiver. Caregiver 10 stated that since she started caring for her husband and parents, she has “missed vacations with our friends for the [past] 10 years...you stop doing everything. People stop coming to see you.”

Concerning the inability to attend their chosen house of worship, three caregivers discussed the importance of church in their lives and, due to providing care, they are no longer able to go to church or spend as much time at church. In the words of Caregiver 3, “I can’t be [at church] any more than two or three hours and I’m on my phone constantly watching her.” Caregiver 12 discussed the reason why she cannot attend church anymore: “I stopped going. I stopped going to church because of the heavy care of my dad...but I haven't been able to get to services because...it takes so long to get Dad up in the morning, and ‘till I get to the services. It just costs too much time. It just wasn't enough time there to do that.”

Alterations in their living environments was shared by six caregivers, including moving from larger houses to smaller houses and moving into their parents’ homes or having their parents move into the caregiver’s home. Caregiver 11 and her wife moved to a Continuing Care Retirement Community in anticipation of additional care that may be necessary. Caregiver 12 stated that she has “no personal space per se...my belongings are all packed into what would have been my old bedroom upstairs.” Caregiver 10 cares for her parents and her chronically ill husband. She reported that she had to “spend 50 grand on upgrades to the house,” adding a water softener, a generator, a second bathroom and cameras throughout the house to be able to watch everyone.

Four caregivers reported that a major change in their life was the loss of their plans for retirement, which was the last subtheme. Caregiver 3’s husband was intending to retire after this year, but he cannot retire now due to the cost to care for his mother-in-law. Caregiver 4 has had to dedicate her last five years caring for her husband in her

retirement. The first two years, her spouse was able to get to doctor's appointments and manage his care. However, his dementia progressively got worse in the past three years, and she has had to take on all of the caretaking responsibilities, with limited help.

The interview participants were asked about the challenges that they have faced when caring for their loved ones and how these challenges have impacted their lives.

Eleven of the twelve individuals noted that that the major challenges they have experienced revolved around not addressing their own mental health and health needs as much as they should. Regarding mental health, seven respondents discussed the stress resulting from the ADRD disease process and the responsibilities of caring for their loved ones. The psychological hardship of watching someone decline in addition to being the brunt of the negative behaviors and personality changes that someone with ADRD exhibits negatively impacted Caregivers 6, 8, and 9. Caregivers 2 and 10 developed depression while caring for their loved ones. Caregiver 10 felt suicidal at times, but told the researchers "but I wouldn't have [attempted suicide]...because I've had so many people in my family do that...I don't like the aftermath."

Many caregivers also discussed the challenges of providing care to their loved one, while having their own physical health issues. Caregivers 3, 5, and 11 had prior health issues before providing care. For them, it was difficult to follow up with their own medical care while caring for the person with ADRD. Caregiver 11 knows that she needs to have hand surgery, but she cannot get it due to the needs of caring for her wife. Caregiver 2 reported that he gained twenty-five pounds and has started to grind his teeth at night, due to the stress of caregiving. Two months after Caregiver 7's husband died, she was admitted to the hospital herself for illness. "I was so focused on his care that I never really thought about myself." Caregiver 12 succinctly stated, "I feel like I am taking better care of them, than I take care of myself."[35]

Four 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. Caregivers 1, 2, and 4 had difficulty navigating the health care system. Caregiver 1 did not understand the medical terminology at first nor did he know about the behavioral and psychological changes that may occur with ADRD. He did research on his own to learn about ADRD. Caregiver 2 stated "There are no resources here" and that he "had to beg for a neurologist [appointment]...and was told it would take six months to get them there, because there was nothing locally available for six months". He is concerned about the people who do not have anyone to care for them and wonders how they find help. Caregiver 4 wished that finding resources would not have to be "this complicated" and was successful in finding help through a social worker at her local hospital, who "was really helpful, [r]eally helpful." However, the social worker left the position over a year ago and the hospital has not yet begun to fill the position.

Caregivers 2, 4, and 12 believed that the attitudes of some medical professionals

[35] Respondent 12 passed away unexpectedly two weeks after the interview was conducted.

hindered their ability to find resources or their understanding of how to interact with a person living with dementia. Caregiver 4 reported that after her husband was diagnosed with ADRD, the medical professional basically said “Go and take care of it yourself. It's not our problem” and did not offer any resources for services. Caregiver 12 recommended that medical personnel working in urgent, emergency, and hospital facilities receive “training on how to engage with a person living with dementia and they need to be trained on good customer service.”

Three respondents discussed the financial challenges they experienced due to caring for their loved one. Caregiver 1 was able to pay for in-home caregivers for his wife, however, their finances have dwindled so much that she became eligible for more financial support through the OPTIONS Program. Caregiver 7 had to cash in their savings to help pay for the necessities needed for her husband’s care and some months they would run out of money, “but there are some people that stepped up and had fundraisers to raise money...and at Christmas [they] would give me money to help pay for those meds that he needed. So, without that I really don't know what I would have done because you go through your resources.” While the Caregiver Support Program allows up to $500 a month to be reimbursed for any supplies, Caregiver 10 did not have $500 in her bank account to spend on supplies that would be reimbursed by the AAA the following month. She “had to go get a loan to get that first amount of money, [because] I'm living paycheck [to paycheck] by credit card.”

During the interviews, the researchers explored what resources the caregivers had used to help them care for their loved ones. Five of the caregivers interviewed had extensive experience either working at agencies or facilities that cared for people with ADRD.

Caregivers tapped into different resources to help them gain more information about the ADRD disease process and caregiving issues. Professional organizations that these caregivers contacted were their local Area Agency on Aging, the Alzheimer's Association, formal support groups, other helpful professional resources, and online professional resources and trainings. Informally, caregivers relied on connections to friends, searching the Internet, and reading books and academic research journal articles to learn about the disease and caregiving. Seven out of twelve caregivers also relied on their prior experience in caring for an individual with ADRD.

Of the 12 caregivers interviewed, 9 of the individuals who are living with ADRD have been connected to or are receiving services from their local AAA. Two people living with ADRD are not connected to their local AAA because the caregiver believed that they would not meet the financial qualifications to receive services. One caregiver was not able to answer the question. While this caregiver is caring for her aunt who has ADRD, her aunt was connected to AAA services before she started providing paid care through the Community HealthChoices program. The caregiver did not have a need to contact her local AAA for any support or resources.

Professional resources that helped the caregivers were in-person or online support

groups sponsored by their local Area Agencies on Aging, the Alzheimer's Association, or another organization. Caregiver 7 discussed her experience with and benefits from a AAA-based support group:

> There's too many people with too many questions, and nobody to answer them, and I know from experience that I needed somebody to talk to, and I didn't have anybody...and I said, You know what we're right. We need to do this. So [the case manager] and I started a support group and asked the county if we could use the facilities at the county to hold this. And she invited all the people that were on her caregiver support program. And that's how it all started.

Caregivers provided information about other resources that helped them learn about the disease and strategies for care management which they found through searching the Internet.[36] Caregivers 1 and 8 contacted their long-term care insurance company and education and services were provided to them for assistance with their caregiving needs. Caregiver 1 also had access to his Elder Care law firm's services to help him plan for providing care.

Seven respondents believed that living in a rural area impacted their access to information and services for themselves and the person with ADRD. According to them, living in a rural area contributed to a lack of home care workers and medical resources, created difficulty in finding information and education, as well as transportation.[37]

Three respondents vocalized that living in a rural area impacts their access to home care workers to provide them with help or respite care. Caregiver 4 stated that there needs to be "much better support for the health care workers. Better pay, better hours, better recruitment, better training. You know they really need to focus on that." Caregiver 6 said that it was difficult to find someone to watch her mother for $10 an hour. She would like to have someone watch over her mother, so she can leave the house when she needs to run an errand. Caregiver 6 asked a home care agency about this type of service, at this price-point, and "they wouldn't come out here for just $10 an hour."

Two caregivers discussed the difficulty of securing necessary medical appointments when living in a rural area. Caregiver 1 believes that telemedicine is an "absolute necessity" since it often takes him two hours or more to go to more specialized appointments for his loved one. Caregiver 2 agreed with the need for more medical

[36] Two respondents discussed their experience with the Penn Memory Center (https://pennmemorycenter.org/) (discussed in more detail in the Policy Considerations section); respondents highlighted the online trainings provided by Teepa Snow (https://teepasnow.com/), Aging Care.com (https://www.agingcare.com/) and the University of Tasmania's Wicking Dementia Research and Education Centre (https://mooc.utas.edu.au/organisation/3/The_Wicking_Dementia_Centre.html).

[37] Respondents who answered this question reported that they had stable internet access, but some recognized that not all caregivers have high quality Internet access.

services and advocated for more clinics in the rural areas for people with ADRD. Caregiver 2 suggested the need for more education about dementia provided to the family medicine practitioners in his rural area.

Caregiver 4 moved from an urban area to a rural environment a decade ago. Since she started caregiving, her computer has been her "lifeline."

> If I didn't have that, I don't know where I would be at this point. I can look to the wider world...I have a support group on Zoom in California...and another group is in Chicago and a couple of groups in Pennsylvania. In other words, I have to look outside this area by thousands of miles just to have any kind of support that is certainly not available here.

One respondent indicated that their access to transportation was more difficult due to living in a rural area. Caregiver 12 stated that where she lives, there is no public transportation at all. Her county provides a Senior Shared Ride service for those who are eligible. However, trips require an advanced reservation, and the person often is picked up extremely early for their appointment and will have to stay later at the facility until they are picked up again. Shared Ride takes up a large part of their day. However, she would use this service for her parents, "if push came to shove, and they couldn't find anybody else."

At the close of the interviews, the respondents had an opportunity to share their perspectives about what they would do if finances were not a concern. Ten family caregivers provided a variety of ideas; the two dominant topics were having more help in their homes and more respite time.

Seven caregivers placed having more caregiving help at the top of their "wish list." Caregiver 2 wished for 24-hour, 7-day a week care for his father at home, noting this is impossible "unless you're a multi-millionaire." Interestingly, Caregiver 2's father resides in a personal care home, but due to the facility being "understaffed," Caregiver 2 provides approximately "two-thirds of his daily needs" at the facility.

> I give him a bath. I brush his teeth, I floss, I get him to gargle, I cut his nails. I do all his bathing. I wash his hair, because otherwise he's not getting it [from the personal care home] probably once every nine days. They have explained to me that they are very shorthanded at the place with help...If I ask for more services...it's more money...If I could spend more time just sitting and talking with him, watching TV, drinking a cup of coffee, putting my arm around him, instead of the hours being spent to bathe him, to brush his teeth...

Caregivers 3, 11, and 12 would also like to have unlimited finances to pay for

additional home care assistance. These caregivers do not want a home care aide to provide total care; they would like someone to help at various times during the day and evening. Caregiver 11 would like to have "more in-home help for her wife with the tough stuff, which is getting her out of bed and getting her into bed at night. She likes to go to bed at 11:00 PM, so it's hard to find somebody who wants to come in for a couple of hours to help me put my wife in bed." Caregiver 12 would like for "someone to come in and help with morning care and to visit with [mom] to engage her." Caregiver 3 would like for the home care worker to "come every other day. I was brought up to care for your family, I do not want the home care worker to be there all of the time. I want to be able to care for mom too." Three caregivers (Caregivers 5, 7, and 12) stated that if they had endless finances, they would use these funds to provide themselves with more time for respite. Caregiver 5 would pay for his mother to stay at the local nursing home "for 2 weeks or so... it would be more experimental, to see if she would like that kind of stuff. And if she did, great! She could probably socialize with more people around her age." This type of use for a respite program could help with planning for when a caregiver can no longer support their loved one.[38]

All caregivers interviewed provided suggestions on how to improve or create policies, programs, and services, if Pennsylvania were to have unlimited finances to be able to do so. Two main themes were developed from their responses: changes to existing policies and the creation of additional programs to help the family caregivers.

Six caregivers discussed the changes to one policy and three programs: Medicaid, Community HealthChoices, OPTIONS Program, and the Caregiver Support Program. Three respondents discussed the expansion of Medicaid's eligibility policy, with two respondents (Caregivers 1 and 12) suggesting additional allocation of funding to pay home care workers higher wages. Caregiver 1 suggested that Medicaid "provide extra funding to raise the wages of caregivers that might attract more people to go in...because every one of the agencies I've talked to, that is their number one issue, and that is they don't have people to staff" all of the caregiving needs. Caregiver 8 discussed the economic hardships that families undergo, ultimately leaving the person with ADRD and the family impoverished and reliant on Medicaid funding "the economics of this disease is horrible. But the burden of this disease is the economics, the loss of finances, someone who is no longer able to take care of themselves. And the burden is on the financial aspect of that couple and that family. In some cases, they were wiped out [financially]."

Four caregivers suggested modifications to the Community HealthChoices program. Two respondents (Caregivers 7 and 12) discussed the need for individuals who hold a

[38] Respondents offered other "wish list" items including being able to purchase assistive devices and get a therapy dog. Respondent 4 told us: "[I would] pack everything up and move to New York City. [T]here's an amazing memory care center there at Mt. Sinai Hospital...[I]t just would reduce the stress greatly trying to coordinate so much to get done here, whereas with unlimited finances, we're out, we're done, we're gone, and we'll go back to the big city."

Power of Attorney to be able to be either compensated or reimbursed for providing care to their loved one with ADRD. Currently, spouses and individuals who hold a power of attorney are not eligible for compensation or reimbursement through the Community HealthChoices Program.[39] Caregiver 7 had to stop working as much to care for her husband, ultimately losing income that was sorely needed. She was not eligible for compensation through the Community HealthChoices program, because they were married.

> Caregivers have to give up their jobs and I will tell you that as a caregiver and a wife, I didn't qualify for any reimbursements. So, I lost my income from my job. And I can't get anything, because I'm not a neighbor down the street who can get the money. I think the qualifications for these programs have to be changed for the ages. Okay, I'm a caregiver. And because I had a job that I made $50,000. But now I'm not gonna make that. And now I'm gonna be a caregiver for my husband. But now that $50,000 is gone, but all these programs...I couldn't get reimbursed for anything because I was his wife. That's unfair.

Caregiver 10 wished that the OPTIONS Program allowed private contractors to provide home care services, not just the home care agencies that the AAAs have contracts with to provide services. Caregiver 6 would like to see the OPTIONS Program provide more financial support for home care workers to able to spend more time than the maximum allotment of hours, which is deemed by the program. Caregiver 6 elaborated:

> Having more available caregivers, agency, or whatever you know to come in and spend more time to give the families a break that who are being the caregivers. If you're paying as a state, a nursing home is $10,000, a month as opposed to maybe having caregivers. That would be, you know, would be half that price. So, I would think that would be a good thing. You know, someone that's not nursing home eligible, or, you know, not bad enough to be in a nursing home. It would be less costly to have more caregivers in the homes...You're paying $10,000 [for the nursing home]. You're not even getting care. They're not even getting the best care that they should have. You know. There [are] days they don't even get bathed, you know, so at least when they're home they get bathed and taken good care of.

Two respondents suggested changes to the Caregiver Support Program. At present, the Caregiver Support Program provides a grant of up to $5,000 for an individual to

[39] See https://www.medicaidplanningassistance.org/pennsylvania-community-healthchoices-program/.

make home modifications to help care for individuals. The grant is attached to the caregiver and not the care recipient (Pennsylvania Department of Aging, n.d.). Caregivers often take care of multiple family members who remain in their homes, as pointed out by Caregiver 10. The grant should be per person who is living with ADRD (or other debilitating medical issues), not for the caregiver who may find themselves providing care to a different family member in the future.

Eleven caregivers provided suggestions for new policies and programs that would better help the caregivers if Pennsylvania had unlimited finances. Three subthemes were developed, such as financial programs, support services, and education and training ideas. Two respondents (Caregivers 7 and 10) believe that all AAAs should provide "seed money" (as opposed to reimbursement) through the Caregiver Support Program (CSP), if someone should need it. Caregiver 7 also discussed the need for "caregiver tax credits" and "a reduced rate or free of charge internet service... [so that caregivers] have some kind of access to communication with the outside world without hurting their budget by getting it on their own."

Support services, particularly help from a "care coordinator," (see the discussion of the "warm hand-off" above) were discussed by more than half of the respondents. Caregiver 5 believed that the local AAA has services helped him navigate the complicated world of caregiving, "but they do fall short a little bit." Caregiver 6 told us that she would have benefited from a program like this, "because there's a lot of things I don't know." Two respondents discussed the need for more specific, tailored plans of care upon the initial diagnosis. Caregiver 11 expanded on her idea by suggesting that a care coordinator:

> See what each of their [caregiver and person with ADRD] individual needs are... like...I need X, Y, and Z. But somebody else needs something else...to kind of have a resource of people that would be available to help each individual with their needs, because everybody's needs aren't going to be the same.

Other wish list programs discussed by family caregivers included "a free clinic to help with dementia and caregiving" that included more counseling services, including more structured support groups (Caregiver 2), and more outdoor recreation programs (Caregiver 3). Caregiver 9 supported having in-home training for family caregivers. This training would include topics such as incontinence issues, meal planning, medication disbursement, and strategies for addressing the behavioral aspects of dementia.

Various caregivers offered additional comments about caregiver education. Caregiver 4 would like to see her local hospital:

> Offer an hour free caregiving course...like, if you're going to move a patient, this is how you could do it, or how you shouldn't do it. You want

> to take blood pressure. This is how you should or shouldn't do it, and on and on and on. If they're [the county] expecting us to pick up the slack, then maybe they want to help us with their expectations...And it can be done, and they won't lose money on it, because they could run it as a volunteer service and you count how many people are coming into your volunteer service, and you get reimbursed by the state and the federal government.

Caregiver 10 would like for the Commonwealth to pay for every caregiver to take Teepa Snow's "$50 course" to learn about the progression of ADRD and the accompanying behaviors. Caregiver 7 discussed training for emergency situations:

> What do you have ready in your house? If there's a storm and your electricity goes out? What if there's a snowstorm and you have no heat? What do you do? Do you have things ready? Do you have medicine packed up in case you have to leave your house in a hurry?

These instances happened to her while caring for her husband and she would have liked to have been more prepared at the time.

Survey of Area Agency on Aging Direct Care Workers

An important group of stakeholders who provide care to individuals with ADRD are the staff members who work at the Area Agencies on Aging. Direct care workers' responsibilities include assessing the person with ADRD, assessing their current living situation, and determining if the person or caregiver is eligible for supportive services. The survey of agency staff was done online using the Qualtrics platform. Data was collected this way because of its efficiency and direct care workers' ability to complete the survey at any time convenient to them. The direct care workers were recruited through e-mails sent by agency directors to staff and an e-mail sent from the Pennsylvania Association of Area Agencies on Aging (P4A). Multiple e-mails were sent and ultimately, thirty-seven staff members responded to the survey.[40]

Of the 37 respondents, 33 worked in rural counties (Blair, Butler, Cambria, Clearfield, Fayette, Greene, Monroe, Venango, and Wayne); the four individuals who worked in urban counties served individuals in Allegheny, Cumberland, and Luzerne counties. Table 16 contrasts the aging care workers from rural counties with those working in urban counties as to the number of years providing aging care services and their perceptions of care quality. Slightly more than half (N=19 or 51.3%) had worked as a direct care worker for more than three years, with another 35 percent (N=37) working between one and

[40] The total number of e-mails sent is unknown and therefore, we cannot calculate the response rate or the margin of error. The survey instrument and frequency distribution for responses is included in Appendix 1.

three years. Direct care workers were asked about their perceptions of care for individuals living with a dementia-related disorder in their county. Only 16.2% (N=6) rated the care as "Good," with 37.8% (N=14) rating the care as "Poor" or "Extremely Poor." Individuals providing care in rural counties were more likely to view care positively as compared to urban workers.

Table 16: Perceptions of Care, by Rural/Urban Status and Length of Time as an Aging Care Worker

		Perception of Care				
		Extremely Poor	Poor	Neutral	Good	TOTAL
Less than six months	Rural	0	0	2	0	2
	Urban	0	0	0	0	0
Six months to one year	Rural	0	1	1	1	3
	Urban	0	0	0	0	0
Between one and three years	Rural	2	4	5	1	12
	Urban	0	1	0	0	1
Between three and five years	Rural	0	0	3	1	4
	Urban	0	0	0	0	0
More than five years	Rural	1	3	6	2	12
	Urban	0	2	0	1	3
TOTAL	Rural	3	8	17	5	33
	Urban	0	3	0	1	4

Source: Bourassa and Grove, Survey of Aging Care Workers, 2023 (N = 37).

Concern about training for direct care workers who interact with individuals with ADRD was an issue raised during interviews with directors of our partner Area Agencies on Aging. Table 17 shows the sources of training reported by agency direct care workers.

Table 17: Sources of Training for Agency Direct Care Workers

Training Provider	Percent Reporting Participating in Training
County Area Agency on Aging	64.9%
Previous Direct Care Work	40.5%
Pennsylvania Department of Aging	35.1%
Alzheimer's Association	29.7%
Dementia Friends	29.7%
Other[#]	27.0%

Source: Bourassa and Grove, Survey of Aging Care Workers, 2023 (N = 37). *Responses falling into this category included: prior training as a nurse, education courses at a college or university, continuing education courses, and training from a previous employer.

The concerns with the labor market noted by other stakeholders were also noted by agency direct care workers themselves. Table 18 shows that more than half of the respondents mention the poor pay associated with their positions. One out of every five respondents also mentioned issues with their training.

Table 18: Identification of Issues Associated with Employment as an Area Agency on Aging Direct Care Worker

Issue	Percentage Reporting Issue as a Concern
Poor pay	55.6%
Lack of experience working with individuals with Alzheimer's disease	27.8%
Lack of training	22.2%
Lack of benefits	16.7%
Lack of transportation	16.7%
Other^	25.0%

Source: Bourassa and Grove, Survey of Aging Care Workers, 2023 (N = 36). *Responses falling into the "Other" category primarily reported that all of the items were issues; the Qualtrics survey had been set to allow only a single response.

Finally, the direct care workers were asked: "If finances were endless, what types of programs or services would you like to see created to help individuals with Alzheimer's disease or a related disorder and their caregivers? Please be creative!" Twenty-nine respondents provided responses to this question with a summary in Table 19.

Table 19: Top Five Suggestions for Programs or Services from Area Agency on Aging Direct Care Workers

Suggestion for Program or Service	Number Offering the Suggestion
Adult day center	13
Additional training	11
Respite care program	9
More in-home services	7
More use of technology	3

Source: Bourassa and Grove, Survey of Aging Care Workers, 2023 (N = 29). The total number exceeds twenty-nine because respondents offered multiple suggestions for programs or services.

Beyond the responses captured in Table 18, one direct care worker suggested "that caregivers should have some kind of mentor that they are able to call" (Direct Care Worker 11), while another supported the creation of a "village where Alzheimer's patients can live together complete with grocery stores, post offices, hair salons...basically a personal care village" (Direct Care Worker 13).

Survey of Home Care Workers

Beyond the direct care workers employed by the Area Agencies on Aging, home care workers who interact with individuals living with dementia and their families understand the caregiving landscape. Data from the Bureau of Labor Statistics (2023) indicate that over 213,000 persons are employed as home health or personal care aides. Working with agency stakeholders, home care workers were recruited to complete the same survey as the agency staff using the Qualtrics platform.[41] Multiple e-mails were sent and ultimately, 77 home care workers responded to the survey.[42]

Concern about training for home care workers who interact with individuals with Alzheimer's disease, or a related disorder was an issue raised during interviews with the directors of our partner Area Agencies on Aging. Table 20 shows the sources of training reported by home care workers.

[41] Because these individuals were not affiliated with the Area Agencies on Aging, respondents who provided their name and physical mailing address were entered into a random drawing to receive a $20.00 Amazon gift card.

[42] Because we used a convenience sample, the total number of e-mails sent is unknown and therefore, we cannot calculate the response rate or the margin of error. The survey instrument is included in Appendix 1.

Table 20: Sources of Training for Home Care Aides

Training Provider	Percent Reporting Participating in Training
Previous Direct Care Work	62.7%
Other*	23.3%
Dementia Friends	14.9%
Alzheimer's Association	13.4%
County Area Agency on Aging	9.0%
Pennsylvania Department of Aging	6.0%

Source: Bourassa and Grove, Survey of Aging Care Workers, 2023 (N = 67).

*Responses falling into this category included: their current or previous employer, prior training as a nurse, family and friends, and obtaining information through online sources.

Home care workers were asked about concerns they had related to their employment. Table 21 shows that their top concern was poor pay, a concern discussed throughout this report by all groups.

Table 21: Identification of Issues Associated with Employment as a Home Care Aide

Issue	Percentage Reporting Issue as a Concern
Poor pay	47.8%
Lack of experience working with individuals with Alzheimer's disease	19.4%
Other+	17.5%
Lack of benefits	13.4%
Lack of training	9.0%
Lack of transportation	3.0%

Source: Bourassa and Grove, Survey of Home Health Care Aides, 2023 (N = 67).

*Responses falling into the "Other" category primarily reported that all of the items were issues; the Qualtrics survey had been set to allow only a single response. In addition to the items specifically listed in the survey, respondents offered "a lack of childcare" and "miscommunication or poor communication" by agencies with employees.

Finally, home care workers were asked to provide their suggestions about programs or services to help individuals with Alzheimer's disease or a related disorder and their caregivers. Forty-six respondents provided responses to this question and their input is summarized in Table 22.

Table 22: Top Five Suggestions for Programs or Services from Home Care Aides

Suggestion for Program or Service	Number Offering the Suggestion
Additional training and dementia education	18
Adult day centers	8
More in-home services	7
Respite care program	3
More use of technology	3

Source: Bourassa and Grove, Survey of Home Health Care Aides, 2023 (N = 46).

The home care workers' suggestions recognize the need for more widespread dementia education, particularly associated with the progression of the disease and changes in behavior. While not associated with specific programs, home care workers stressed the theme of keeping the individual living with dementia active. Activities, such as those provided at an adult day center, were shared, but activities in the home, including puzzles and picture boards, were mentioned. As one home care aide wrote: "[Give] the caregivers tools to keep them occupied and not in front of the T.V."

Innovative ADRD Programs, Support and Resources

This project conducted a search for innovative programs and their sources of support for individuals living with a dementia-related disorder in the United States. Appendix 4provides a list of programs, their website, a brief description, and the sources of funding. Most of the programs are privately funded, relying on charitable contributions and grants to support their work.

Shifting the focus of the search for innovative programs to programs which already have a foothold in Pennsylvania and showcasing their expansion yields more practical information. This section highlights three innovative programs: Dementia Live, Dementia Friends, and the Penn Memory Center.

Dementia Live uses virtual reality technology to simulate what it means to have dementia and is designed for any person. This program promotes greater understanding of the progression of dementia as well as the challenges individuals living with dementia face in completing routine activities of daily living. The program takes thirty minutes and has been sponsored by health care organizations across the state (see the recent article from *Berks Regional News*, "Dementia simulation experience helps create a better understanding of the disease," 12/12/23).

Dementia Friends is a global initiative aimed at building dementia-friendly communities. Using interactive workshops, both in person and online, the program's goal is to help individuals understand the world of individuals living with dementia. Generating awareness about the behavioral aspects of dementia can help reduce the stigma associated with the disease. Pennsylvania is home to seven dementia-friendly communities – Doylestown, Greater Pittsburgh, Lancaster, Lehigh Valley, Newtown, Susquehanna Valley, and York/Adams County.[43] These programs represent grassroots efforts to improve the lives of individuals living with dementia and their caregivers. Dementia Friendly Susquehanna Valley (DFSV)[44] provides an example of leveraging community partnerships to help this vulnerable population. DFSV is led by individuals working at a law firm which specializes in elder law who have built a team that encompasses local law enforcement, businesses, educational institutions, and social service agencies. DFSV works with physicians and health care facilities to promote earlier detection and more comprehensive treatment for individuals living with ADRD diseases.

As a program affiliated with a medical school, Penn Memory Center is a "source for those age 65 and older seeking evaluation, diagnosis, treatment, information, and research opportunities related to symptoms of progressive memory loss, and accompanying changes in thinking, communication and personality" (Penn Memory Center, 2024). The Center uses a multi-disciplinary approach to treat individuals living with dementia and to support their caregivers that encompasses cognitive neurology, geriatric medicine and psychiatry, and includes clinical professionals from neuropsychology, psychometrics, nursing, psychotherapy, social work, and research management.

[43] Cumberland County has an inactive dementia-friendly community. It is currently seeking a community leader.

[44] See Dementia Friendly Susquehanna Valley's website at: https://www.dementiafriendlypa.org/dementia-friendly-communities/current-communities/susquehanna-valley.

Discussion and Conclusions

This research provides additional evidence about the complex questions surrounding the prevalence of Alzheimer's disease and related disorders and the challenges facing the network of individuals who provide care, whether it is formal or informal. The projections from the Alzheimer's Association about the number of individuals who will be living with this disease are staggering with 13 percent of Pennsylvanians having the disease by 2040.

While the total population in Pennsylvania's rural counties will decline over the next twenty years, the proportion of the population age 65 and older in those counties will increase (see Tables 3 and 4). Given that age is the number one risk factor for Alzheimer's disease, rural counties will experience an increased need for services for this population. Adding the risk factors of smoking and obesity amplifies the concerns. At current rates, smoking and obesity contribute an additional 45,963 Alzheimer's cases. An aging population with high rates of smoking and obesity suggests the need to review care options and make plans for the surge in demand.

Given the present capacity, the shortage of long-term care facilities in the Commonwealth will be acute; this will be particularly true in rural counties which already have few options for institutional care for individuals with Alzheimer's disease or a related disorder (see Figures 1, 4, and 8). Trends over the last two decades suggest that even fewer institutional options will exist as labor shortages and inadequate government reimbursement force facilities to close. With decreasing numbers of institutional options and the overwhelming preference of older adults to age in place, increased demands for home health and personal care services are on the horizon.

Interviews with Area Agencies on Aging in rural counties and statewide advocacy groups demonstrate the picture will be no better for access to home care services. All of the directors of the Area Agencies on Aging who participated in this project indicated that they did not have sufficient resources, either from public or private sources, to cover the needs of individuals living with ADRD and their caregivers. Advocacy organization stakeholders echoed this theme, noting there needs to be more money allocated to help people with Alzheimer's disease to age in place.

The directors from the Area Agencies on Aging and the representatives of advocacy organizations acknowledged the challenges of providing services for individuals with an ADRD diagnosis. Both groups discussed the shortage of individuals willing to work with older adults, particularly in home settings, because of low levels of compensation and transportation challenges. Direct care workers are not paid well with the average pay for a home care worker in Pennsylvania at $13.35 per hour, over $5.00 less per hour than a hand laborer in a Pennsylvania distribution warehouse. Furthermore, home care workers are typically paid only for the time they spend with the individual needing care and not for their travel time. Because of low reimbursement rates from Medicare and Medicaid, home care agencies cannot afford to increase their workers' pay or cover their transportation time. These shortfalls will push the care burden onto families.

From the families' perspective, the system for providing care for individuals living with Alzheimer's disease is overly complicated, with program requirements that are burdensome. Combined with a paucity of formal aging services in rural areas and lack of interest for jobs in the home health care sector, family caregivers need more support to take care of their loved one with ADRD. As Caregiver 7 stated: "Family caregivers are the backbone of the long-term care system."

One point resonated with all stakeholders: Pennsylvania needs to dedicate more resources to caring for individuals with Alzheimer's disease or a related dementia. Strengthening existing programs and creating innovative solutions is paramount given the increased need for services coming within the next fifteen years.

Policy Considerations

Organizational stakeholders and family caregivers, as well as the surveys of Area Agency on Aging direct service workers and home care workers suggest the need for changes in the existing support systems to promote a more holistic and financially sustainable model going forward. Three areas for policy considerations have emerged: 1) program eligibility requirements; 2) program and service provision for individuals living with Alzheimer's disease or a related disorder; and 3) education and communication efforts to advance training and understanding of individuals living with dementia.

Program Eligibility for Families Living with Alzheimer's Disease

- Review the Community HealthChoices Program policy regarding payment for spouses or individuals holding powers of attorney.

Because Alzheimer's disease often coincides with end-of-life planning, decisions affect not only the individual living with the disease, but also their families. Individuals often choose a family member when granting a power of attorney. In fact, this is the general suggestion offered by the American Bar Association (2024). Under Pennsylvania law, a spouse or a person holding a power of attorney are not eligible to receive compensation under the OPTIONS and the Community HealthChoices Programs. Appendix 5 lists the 23 states and their programs that permit spouses to receive compensation under the auspices of a caregiver support program.

While spouses account for 25 percent of caregiving at home, daughters account for 39 percent and sons account for an additional 17 percent (Population Reference Bureau, 2020). The current provisions under Pennsylvania law can effectively deny up to 81 percent of caregivers from being eligible for caregiver support.

Program and Service Provision

- Provide "seed money" through the Area Agencies on Aging to assist individuals with limited financial resources when they become family caregivers.

Advocacy stakeholders and family caregivers supported two changes to the Caregiver Support Program. The first change is to offer caregivers an opportunity to have "seed money" when they enter the program. A formalized program would help those caregivers who cannot afford to spend $600 for their first month of purchases. The second change is to attach the once-in-a-lifetime grant of $5,000 for home modification to a care recipient and not the caregiver. Interviews with family caregivers, as well as the surveys of the direct and home care workers, provide a glimpse into the inter-generational nature of caregiving.

- Pass legislation to provide a state tax credit for eligible family caregivers.

To encourage individuals to enter a career in caregiving, the Commonwealth could offer tax credits to work in the long-term care industry or as a family caregiver. Oklahoma became the first state in the country to pass legislation that offers caregivers a tax credit. The Caring for Caregivers Act gives "eligible family caregivers a tax credit of up to $2,000 a year starting in the 2024 tax year, or up to $3,000 a year if the person being cared for is a veteran or has dementia" (Missakian, 2023). Tax credits have been used by the Commonwealth to incentivize individuals to take on service roles in volunteer firefighting and nonprofit emergency medical service agencies (Act 172 of 2016). This policy recommendation would require new legislation like Act 172.

- Create a program that gives individuals a tax-free way to save for long-term care.

The Pennsylvania Department of Human Services coordinates the PA Achieving a Better Life Experience (ABLE) Savings Program for individuals with qualifying disabilities. The PA ABLE Program allows for individuals and their families to set aside funds, tax-free, to use for disability-related expenses. This savings program does not interfere with an individual's eligibility to receive benefits.

While long-term care insurance is available within the Commonwealth, its costs are typically prohibitive for most Pennsylvanians. Creating a program like the PA ABLE program for long-term care needs could help lessen the financial burden on family caregivers.

- Review the process for licensing adult day centers in the Commonwealth, including the establishment of a liaison at the Pennsylvania Department of Aging to assist business owners who starting a center.

While the Pennsylvania Department of Aging and Department of Human Services provide funding to eligible consumers for adult day care services, the lack of program availability in rural areas is problematic. As shown in Figure 7 and discussed by each group of stakeholders interviewed, adult day centers provide caregivers a much-needed break as well as providing the individual living with dementia an opportunity to socialize in a safe environment. Considering that one-third of individuals living in long-term care facilities have dementia, increasing the availability of adult day care will reduce the reliance on institutional long-term care placements. For example, the Department of Aging could provide assistance as individuals and entities navigate the lengthy licensure

process for opening a new facility. This would allow individuals living with Alzheimer's disease and other dementia-related disorders to remain where they want to be – with their loved ones.

Education and Communication

- Implement the concept of a "warm handoff" between physician and social services following the diagnosis of Alzheimer's disease or a related disorder.

Developing partnerships with hospitals and medical practices to create a "warm hand-off" service could be implemented via the AAAs or other agencies. The "warm hand-off" program would employ a social worker to become the care navigator for the individual newly diagnosed with dementia. The social worker would provide any assistance that may be required and continuously follow up with the person with ADRD and their family caregiver until services were no longer needed. Examples of this approach include the work done at Penn Medicine's Alzheimer's and Memory Care Practice at Lancaster General Hospital and the Wright Center for Community Health-Alzheimer's and Dementia Care Program in Scranton.[45] Building these partnerships could include educating family practitioners who work in rural areas about ADRD (including the identification of early warning signs) and programs available to individuals.

Furthermore, in July 2023, the Centers for Medicare and Medicaid Services (CMS) introduced a new model for dementia care. The Guiding an Improved Dementia Experience (GUIDE) Model "will focus on dementia care management and aims to improve quality of life for people living with dementia, reduce strain on their unpaid caregivers, and enable people living with dementia to remain in their homes and communities" (CMS.gov, 2023). The GUIDE Model will provide "care coordination and care management, caregiver education and support, and respite services" (CMS.gov, 2023). This innovative model addresses President Biden's Executive Order 14095 on Increasing Access to High-Quality Care and Supporting Caregivers (Federal Register, 2023).

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

At present, an individual working for an Area Agency on Aging completes a basic aging training program upon hiring; there is no requirement for annual training. The majority of the Area Agency on Aging directors who participated in this study actively encourage their workers to participate in additional trainings, which are beneficial not only for the worker, but also the individual receiving care and the family. In addition, directors discussed the need for improvements in the training provided by the Pennsylvania Department of Aging, to include more instruction on different types of dementia, the disease progression, and best practices for care.

[45] See the organizations' websites at: https://www.lancastergeneralhealth.org/services-and-treatments/neurosciences/programs-and-services/alzheimers-memory-care-and-dementia and (https://thewrightcenter.org/services/alzheimers-dementia/.

Beyond struggling with medical appointments and finances, family caregivers expressed the need for training to manage activities of daily living as well as emergencies. Individuals living in rural communities who may not have a computer, tablet, or smart phone or access to reliable internet connections face challenges accessing training.

Sharing information about Alzheimer's disease and its progression needs to go beyond those working in aging services and family members to the community at large. Training provided by groups such as Dementia Friends can help individuals, including primary care providers, recognize the early warning sings related to the onset of ADRD. Increased awareness about the Alzheimer's disease can help reduce the stigma for those living with it and their caregivers.

- Continue to promote efforts to reduce smoking and obesity rates across the Commonwealth in order to reduce the number of cases of Alzheimer's disease.

While the greatest risk factors associated with the onset of Alzheimer's disease are older age and genetics, reducing the rates of smoking and obesity will reduce the overall number of cases of the disease. Efforts from the Pennsylvania Department of Health to promote smoking cessation (the PA Free Quitline) and obesity prevention (the State Physical Activity and Nutrition grant program) need to have more exposure to the public.

References

Administration for Community Living. (2023). "Older Americans Act." Retrieved from https://acl.gov/about-acl/authorizing-statutes/older-americans-act#:~:text=Congress%20passed%20the%20Older%20Americans%20Act%20%28OAA%29%20in,and%20personnel%20training%20in%20the%20field%20of%20aging.

Agency for Healthcare Research and Quality. (2017). "Warm Handoff: Intervention – Patient and Family Engagement in Primary Care." Retrieved from https://www.ahrq.gov/patient-safety/reports/engage/interventions/warmhandoff.html.

Aging Care.com. (n.d.) Retrieved from https://www.agingcare.com/.

Alzheimer's Association. (2022). *2022 Alzheimer's Disease Facts and Figures.* Chicago, Illinois. Retrieved from https://doi.org/10.1002/alz.12638.

Alzheimer's Association. (2023, April). "2023 Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia* 19(4): 1598-1695. https://doi.org/10.1002.alz.13016.

Alzheimer's Association. (2023). *2023 Alzheimer's Disease Facts and Figures: Special Report* – The Patient Journey in an Era of New Treatments. Chicago, Illinois. Retrieved from https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf.

Alzheimer's Association. (2022). *Pennsylvania*. Retrieved from https://www.alz.org/professionals/public-health/state-overview/pennsylvania.

Alzheimer's Research UK. (n.d.). *All You Need To Know About Smoking and Dementia*. Retrieved from https://www.alzheimersresearchuk.org/news/all-you-need-to-know-about-smoking-and-dementia.

American Association of Retired Persons. (2024) "AARP Network of Age-Friendly States and Communities," Retrieved from https://www.aarp.org/livable-communities/network-age-friendly-communities/.

American Bar Association. (2024). "Power of Attorney." Retrieved from https://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/power_of_attorney/.

American Council on Aging. (2022, March 4). "Nursing Home Costs by State and Region." Retrieved from https://www.medicaidplanningassistance.org/nursing-home-costs/.

Berks Regional News, "Dementia simulation experience helps create a better understanding of the disease," 12/12/23).

Bleibel, Malak, Ali El Cheikh, Najwane Said Sadier, and Linda Abou-Abbas. (2023). "The effect of music therapy on cognitive functions in patients with Alzheimer's disease: a systematic review of randomized controlled trials" *Alzheimer's Research & Therapy*, 15, 65. https://doi.org/10.1186/s13195-023-01214-9.

Boden, Sarah. (2023). "As the number of Pennsylvanians with Alzheimer's grows, so will the burden on caregivers." WESA, March 16, 2023. Retrieved from https://www.wesa.fm/health-science-tech/2023-03-16/pennsylvania-alzheimers-caregivers-medical.

Bramer, Wichor M., Gerdien B. de Jonge, Melissa L. Rethlefsen, Frans Mast, and Jos Kleijnen. (2018, October). "A systematic approach to searching: an efficient and complete method to develop literature searches." *Journal of the Medical Library Association*: 531-541.

Bureau of Labor Statistics. (2022). "Occupational Employment and Wage Statistics." Retrieved from https://www.bls.gov/oes/current/oes_pa.htm#top.

Center on Budget and Policy Priorities. (2023, Feb. 13). "Pennsylvania: Supplemental Nutrition Assistance Program." Retrieved from https://www.cbpp.org/sites/default/files/atoms/files/snap_factsheet_pennsylvania.pdf.

Centers for Medicare & Medicaid Services. (2023). "Guiding an Improved Dementia Experience (GUIDE) Model." Retrieved from https://www.cms.gov/priorities/innovation/innovation-models/guide

Davis, Michelle. (2021, November 8). "Despite Pandemic, Percentage of Older Adults Who Want to Age in Place Stays Steady." Retrieved from https://www.aarp.org/home-family/your-home/info-2021/home-and-community-preferences-survey.html.

Deppin, Colin and Juliette Rihl. (2021, September 2). "The coming crisis in dementia care and why Pa. is woefully unprepared." Spotlight PA. Retrieved from: https://www.spotlightpa.org/series/crisis-of-care/.

Dhana, Klodian, Todd Beck, Pankaja Desai, Robert S. Wilson, Denis A. Evans, and Kumar B. Rajan. (2023). "Prevalence of Alzheimer's disease dementia in 50 US states and 3142 counties: A population estimate using the 2020 bridged-race postcensal from the National Center for Health Statistics." *Alzheimer's and Dementia* 19 (10): 4388 – 4395. https://doi.org/10.1002.alz.13081.

Dumurgier, Julien and Séverine Sabia. (2021). "Life expectancy in dementia subtypes: exploring a leading cause of mortality." *The Lancet Healthy Longevity* 2 (8): e449-e450. https://doi.org/10.1016/S2666-7569(21)00166-5.

Durazzo, Timothy C., Niklas Mattsson, and Michael W. Weiner. (2014). "Smoking and increased Alzheimer's disease risk: A review of potential mechanisms." *Alzheimer's & Dementia* 10(3): S122-S145. https://doi.org/10.1016/j.jalz.2014.04.009.

Dushi, Irena and Brad Trenkamp. (2021). "Improving the Measurement of Retirement Income of the Aged Population." ORES Working Paper No. 116. Retrieved from https://www.ssa.gov/policy/docs/workingpapers/wp116.html.

Eisenmann, Yvonne, Heidrun Golla, Holger Schmidt, Raymond Voltz, and Klaus Maria Perrar. (2020). "Palliative Care in Advanced Dementia." *Frontiers in Psychiatry* 11:699. doi: 10.3389/fpsyt.2020.00699

Emblad, Shayla Y.M. and Elizabeth B. Mukaetova-Ladinska. (2021). "Creative Art Therapy as a Non-Pharmacological Intervention for Dementia: A Systematic Review." *Journal of Alzheimer's Disease Reports* 5(1): 353-364. https://doi.org/10.3233/ADR-201002.

Executive Office of the President. (2023, April 21). "Increasing Access to High-Quality Care and Supporting Caregivers. 88 Fed. Reg. 24669. Retrieved from https://www.federalregister.gov/documents/2023/04/21/2023-08659/increasing-access-to-high-quality-care-and-supporting-caregivers.

Fountaine, A.R., M.M. Iyar, and L.D. Lutes. (2023). "Examining the Utility of a Telehealth Warm Handoff in Integrated Primary Care for Improving Patient Engagement in Mental Health Treatment: Randomized Video Vignette Study." *JMIR Form Res* 7: e40274.

Kaiser Family Foundation. (2016). "The Pennsylvania Health Care Landscape." Retrieved from https://www.kff.org/health-reform/fact-sheet/the-pennsylvania-health-care-landscape/.

Mather, Mark, and Paolo Scommegna. (2020, May 28). "The Demography of Dementia and Dementia Caregiving." Population Reference Bureau. Retrieved from https://www.prb.org/resources/the-demography-of-dementia-and-dementia-caregiving/#:~:text=Overall%2C%20daughters%20provide%20the%20bulk,have%20multiple%20caregivers%20sharing%20tasks.

Missakian, Natalie. (2023, June 12). "Oklahoma Passes Tax Credit for Family Caregivers." AARP. Retrieved from https://states.aarp.org/oklahoma/oklahoma-passes-tax-credit-for-family-caregivers.

Montgomery County, Pennsylvania (2024). "Community HealthChoices." Retrieved from https://www.montgomerycountypa.gov/3038/Community-HealthChoices

Montgomery County, Pennsylvania (2024). "Community HealthChoices: Adult Benefit Package." Retrieved from https://www.montgomerycountypa.gov/DocumentCenter/View/21505/website-document-1

Pennsylvania Department of Aging. (2024). Older Adult Protective Services Act, 35 Pa.C.S. § 10225.101 et seq. Retrieved from https://www.aging.pa.gov/organization/advocacy-and-protection/Documents/Older%20Adults%20Protective%20Services%20Act.pdf.

Paying for Senior Care. (2024). "Spouses Can Be Paid Caregivers for Their Husbands or Wives." Retrieved from https://payingforseniorcare.com/paying-spousal-caregivers.

Pennsylvania Department of Aging. (2024). "About us." Retrieved from https://www.aging.pa.gov/organization/about-us/Pages/default.aspx

Pennsylvania Department of Aging. (2024). Aging Services. Retrieved from https://www.aging.pa.gov/aging-services/Pages/default.aspx

Pennsylvania Department of Aging. (2009). Aging Program Directive 09-01-03. Retrieved from https://www.aging.pa.gov/publications/aging-program-directives/Program%20Area%2001%20%20AAA/APD%2009-01-03%20Contract%20Procurement.pdf

Pennsylvania Department of Aging (2024). Caregiver Support Program. Retrieved from https://www.aging.pa.gov/aging-services/caregiver-support/Pages/default.aspx

Pennsylvania Department of Aging. (2022). Caregiver Support Program. Retrieved from https://www.aging.pa.gov/publications/policy-procedure-manual/Documents/Chapter%20VI%20Caregiver%20Support%20Program%20-%2008.01.22.pdf.

Pennsylvania Department of Aging (2024). Help at Home (OPTIONS). Retrieved from https://www.aging.pa.gov/aging-services/help-at-Home/Pages/default.aspx
Pennsylvania Department of Health. (2023). Nursing Home Reports. Retrieved from

https://www.health.pa.gov/topics/HealthStatistics/HealthFacilities/NursingHomeReports/Pages/nursing-home-reports.aspx

Pennsylvania Department of Aging. (2014). *Pennsylvania (PA) State Plan for Alzheimer's Disease and Related Disorders.* Retrieved from https://www.aging.pa.gov/publications/alzheimers-related-disorders/Documents/Pennsylvania%20State%20Plan%20for%20Alzheimer's%20Disease%20and%20Related%20Disorders.

Pennsylvania Department of Drug and Alcohol Programs. (2024). "Warm Handoff." Retrieved from https://prdddap.pwpca.pa.gov/Pages/Warm-Hand-Off.aspx.

Pennsylvania Department of Human Services. (2024). "Welcome to Community HealthChoices!" Retrieved from https://www.dhs.pa.gov/HealthChoices/HC-Services/Pages/CHC-Main.aspx.

Pennsylvania Department of Human Services. (n.d.) "Who gets Medicaid in PA?" Retrieved from https://www.dhs.pa.gov/docs/Publications/PublishingImages/Infographic-Who%20Gets%20Medicaid.pdf.

Pennsylvania Health Care Association (2022, July 12). "Long-term care receives priority in Pennsylvania's budget with historic investments in senior care." Retrieved from https://www.phca.org/news/press-releases/long-term-care-receives-priority-in-pennsylvanias-budget-with-historic-investments-in-senior-care/.

Pennsylvania Health Care Association. (2024). "The Need for Long-Term Care Continues to Grow." Retrieved from https://www.phca.org/for-consumers/research-data/long-term-and-post-acute-care-trends-and-statistics/.

Positive Approach to Care (Teepa Snow). (2022). Retrieved from https://teepasnow.com/.

Sanderson, Dana, Sandra Braganza, Kaitlyn Philips, Tashi Chodon, Renee Whiskey, Patrizia Bernard, Andrea Rich, and Kevin Fiori. (2021, Jan. – Dec.). "Increasing Warm Handoffs: Optimizing Community Based Referrals in Primary Care Using QI Methodology." *J Prim Care Community Health*. https://doi.org/10.1177/21501327211023883.

Scheltens, Philip, Bart De Strooper, Miia Kivipelto, Henne Holstege, Gael Chételat, Charlotte E. Teunissen, Charlotte E., Jeffrey Cummings, and Wiesje M. van der Flier. (2021). "Alzheimer's disease." *Lancet* 397: 1577-1590. https://doi.org/10.1016/S0140-6736(20)32205-4.

SeniorCare.com. (2024). "Pennsylvania Adult Day Care." Retrieved from https://www.seniorcare.com/adult-day-care/pa/.

TruCare Home Services. (2022, February 11). "The Process to Getting Your HHA Certification." Retrieved from https://www.trucarehomecare.com/how-to-get-hha-certificate-in-pennsylvania/.

United States Bureau of Labor Statistics. (2022). "Occupational Employment and Wage Statistics." Retrieved from https://www.bls.gov/oes/current/oes_pa.htm#top

United States Social Security Administration. (2023). "Fact Sheet Social Security." Retrieved from https://www.ssa.gov/news/press/factsheets/basicfact-alt.pdf.

University of Pennsylvania, Penn Memory Center. (YEAR). Retrieved from https://pennmemorycenter.org/)

University of Tasmania, Wicking Dementia Research and Education Centre. (YEAR). Retrieved from https://mooc.utas.edu.au/organisation/3/The_Wicking_Dementia_Centre.html

Weissert, W. G., J.M. Elston, E. J. Bolda, W. N. Zelman, E. Mutran, and A.B. Mangum. (1990). *Adult day care: Findings from a national survey*. Baltimore, Maryland: Johns Hopkins University Press.

Yahaya, Hassan. (2022, March 15). "New blood test may accurately detect Alzheimer's disease." *Medical News Today*, Retrieved from https://www.medicalnewstoday.com/articles/new-blood-test-may-accurately-detect-alzheimers-disease?utm_source=ReadNext.

Appendix 1: Approved Institutional Review Board Informed Consent, Interview Guides, Qualtrics Surveys

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

Project Director
Dr. Dara Bourassa
Professor
Department of Social Work and Gerontology
Shippensburg University
Shippensburg University
1871 Old Main Drive
Shippensburg, Pennsylvania 17257
717-477-1969
dpbourassa@ship.edu

Co-Principal Investigator
Dr. Sara Grove
Professor
Department of Political Science
Shippensburg University
Shippensburg University
1871 Old Main Drive
Shippensburg, Pennsylvania 17257
717-477-1666
sagrov@ship.edu

Purpose
The purpose of this qualitative research project is to develop a comprehensive assessment of dementia care in Pennsylvania from 2010 to 2034, identify any potential gaps existing in the network that is providing dementia care in Pennsylvania from 2023 through 2034, and to identify innovative programs that exist to address the needs of individuals with Alzheimer's Disease and Related Disorders (ADRD) and their caregivers.

As part of this study, you will be asked a series of open-ended questions. As a participant, you can choose whether the interview will take place face-to-face, using ZOOM, or by telephone.

If you decide to participate, Drs. Bourassa and Grove will ask you to discuss your thoughts and experiences on the past, current, and future needs for those working and caregiving for people with ADRD in rural Pennsylvania. There is no set time limit for the interview, and you can take as long as you wish. The researchers will ask you if you agree to have a recording made of the interview. If you agree, the interview will be recorded, and a transcript will be created. The researchers will use the transcript to develop programmatic, service, and policy recommendations related to the study.

Participant's Rights
Your participation in this project is voluntary. You will be asked if the researchers may use your name in the final report; you have the right to request anonymity. If you request anonymity, you will be assigned a pseudonym instead. If you request anonymity, no one will be able to identify you when the results are reported, and your name will not appear anywhere in the written report. You may skip any questions that you do not wish to answer or complete. You may choose not to participate or withdraw at any time during the study without penalty or loss of benefits or rights to which you might otherwise be entitled. Your consent form will be kept separate from the data records to ensure confidentiality.

Data will be stored electronically on a password protected folder in a shared drive through Shippensburg University. Only the principal investigators will have access to this folder. Devises used to access the electronic data in the shared folder will have an automatic logout feature after being idle for five minutes. In accordance with federal policy, data will be maintained for three (3) years.

You may request a copy of the completed research report following its approval by the Center for Rural Pennsylvania.

Risks and Benefits
Some possible negative effects might be that this study may bring on past pains and memories of experiences when discussing dementia, dementia care, and access to services. If you experience a negative emotional reaction, distress, or a traumatic episode, the researchers will provide you with contact information for mental health resources.

If you have any questions about this study, please ask them now or anytime throughout the study by contacting the Project Director (dpbourassa@ship.edu), the Co-Principal Investigator (sagrov@ship.edu) or caregivingstudy@ship.edu.

If you have questions pertaining to your rights as a research participant or to report objections to this study, you should contact:

Dr. Matthew Ramsey
Institutional Review Board Chairperson
Department of Human Communication Studies
Shippensburg University
1871 Old Main Drive
Shippensburg, Pennsylvania 17257
717-477-1563
mcramsey@ship.edu

The Shippensburg University Institutional Review Board (IRB) has approved the use of human participants for this study.

I understand the nature of this study and agree to participate. I acknowledge that I am at least eighteen (18) years old, and that I understand my rights as a research participant as outlined in the consent form. I acknowledge that my participation is fully voluntary. I received a signed copy of my consent. I give the Principal Investigators permission to present this work in written or oral form for teaching or presentations to advance the knowledge of science or academia, without further permission from me.

_____
Participant Name (Please print.)

_____ _____
Participant Signature Date

Caring for Pennsylvanians with Dementia and Related Disorders: An Analysis of Needs and Capacity in Rural Areas, 2024-2034
Semi-Structured Interview Guide Questions

Area Agency on Aging Staff

1. Please state your name, position, and your general work history.

2. What prompted you to work with the aging population? What about the aging population with Alzheimer's Disease and Related Disorders (ADRD)?

3. What are your perceptions of service provision for people with ADRD and their caregivers in your area?

4. Do you think that you had adequate information and training when working with caregivers and people with ADRD? What did your training consist of?

5. Do you think that caregivers have adequate information and training to care for the individuals with ADRD?

6. Do you think that due to the rural location of your county, it is more or less difficult to provide education and information to those caring for people with ADRD? Why or why not? If you have had difficulty securing information and services for your consumers in the past, do you have any ideas on how you could change this? What could be improved?

7. What are the agencies or companies that you usually partner with to provide education, information, or assistance for ADRD caregivers? What are the strengths and weaknesses in accessing these services for your clients?

8. Do you think that the money allocated to your county (publicly and privately) is enough to cover all of the needs of the caregivers and those with ADRD?

9. Existing literature suggests that workforce training and financing issues are identified as areas where gaps exist in providing dementia care. What do you see as the major issues where gaps exist in providing dementia care for the caregivers and people with ADRD in your county?

10. If finances were endless, what types of programs or services would you like to see created to help caregivers and those with ADRD?

Caring for Pennsylvanians with Dementia and Related Disorders: An Analysis of Needs and Capacity in Rural Areas, 2024-2034
Semi-Structured Interview Guide Questions

Advocacy Organizations

1. Please state your name, position, and your general work history.

2. What prompted you to work with the aging population? What about the aging population with Alzheimer's Disease and Related Disorders (ADRD)?

3. The State Plan on Aging 2020-2024 (Plan) seeks to involve the AAAs more fully in providing services to individuals with dementia and their caregivers. What are your thoughts about why this was in the 2020-2024 plan?

4. Existing literature suggests that workforce training and financing issues are identified as areas where gaps exist in providing dementia care. What do you see as the major issues where gaps exist in providing dementia care?

5. What are the common questions or requests your organization receives regarding service provision? Does your organization get contacted by individual caregivers? If so, what are the types of questions they have? How do you help them answer their questions?

6. What are the common questions or requests for services that you hear the most from caregivers? How do you help them answer their questions?

7. If finances were endless, what types of programs or services would you like to see created to help caregivers and those with ADRD?

NOTE: The interview guide was modified for each advocacy organization. Copies of all interview guides will be shared upon request.

Caring for Pennsylvanians with Dementia and Related Disorders: An Analysis of Needs and Capacity in Rural Areas, 2024-2034
Semi-Structured Interview Guide Questions

Family Caregivers

1. Please state your name, who you are caring for, and how long you have been caring for the person with ADRD? Do you live with the person with ADRD, commute to their home, or do they live with you?

2. Have you had any previous experience caring for someone with ADRD?

3. How was the decision made that you would be caring for someone with ADRD? (a lack of finances for in home care or SNF, family member request, any other reason)

4. Is there a stigma or pressure in your community that an individual with ADRD must be taken care of at home by friends/family?

5. What were the changes that you had to make in your life to start to care for someone with ADRD?

6. Have you gained any benefits from caring for someone with ADRD?

7. What are the challenges of caring for someone with ADRD? Have these challenges impacted your finances, physical/psychological health, general well-being?

8. What were some of the initial concerns you had when you contacted the local AAA for help? Were there any barriers in accessing information or services?

9. Have you utilized any resources to help you gain more information about ADRD and how to care for someone with ADRD? Can you give an example of something that you do in providing care that is a result of a resource you used? What would you like to have seen differently if you were to utilize these resources again?

10. Did you feel prepared to care for the individual with ADRD? If not, what would you have wanted to know about caring for someone with ADRD?

11. Do you feel like you are still providing adequate care for the individual with ADRD? Have you discussed any plans in case you cannot provide care anymore? Do you have an idea about what circumstance(s) would make it impossible for you to provide care any longer? What would that be?

12. Do you feel that living in a rural area has impacted your access to information and services? If so, how has it impacted you? How could you change this?

13. If there were unlimited finances to allow you to continue to care for your individual with ADRD, what would be on your wish list? What would help you the most? The least?

14. If Pennsylvania had unlimited finances, what policies and programs would you like to see implemented for the caregivers?

Survey of Aging Care Workers
Administered through Qualtrics
Data Collected September 27, 2023 through November 21, 2023
Data File: Excel – Aging Care Workers Raw Data from Qualtrics

Thank you for visiting our link to the project: "Caring for Pennsylvanians with Dementia and Related Disorders: An Analysis of Needs and Capacity in Rural Areas, 2024-2034." This project has been approved by the Shippensburg University Institutional Review Board (IRB) which requires that we provide the following disclosures associated with this project.

Please read the Informed Consent document below. After reviewing the document, click on "Yes" to start the survey. Clicking on the link notes that you have read and understood the scope of this project. If you have any questions, please contact us at caregivingstudy@ship.edu. Informed Consent Project Director Co-Principal Investigator Dr. Dara Bourassa, Professor, Department of Social Work and Gerontology, Shippensburg University, 1871 Old Main Drive, Shippensburg, Pennsylvania 17257, 717-477-1969, dpbourassa@ship.edu Project Director Co-Principal Investigator Dr. Sara Grove, Professor Emeritus, Department of Political Science, Shippensburg University, 1871 Old Main Drive, Shippensburg, Pennsylvania 17257, 717-477-1718, sagrov@ship.edu.

Informed Consent

Purpose -- The purpose of this qualitative research project is to develop a comprehensive assessment of dementia care in Pennsylvania from 2010 to 2034, identify any potential gaps existing in the network that is providing dementia care in Pennsylvania from 2023 through 2034, and to identify innovative programs that exist to address the needs of individuals with Alzheimer's Disease and Related Disorders (ADRD) and their caregivers. As part of this study, you will be asked a series of multiple choice and open-ended questions.

Participant's Rights -- Your participation in this project is voluntary. You may skip any questions that you do not wish to answer or complete. You may choose not to participate or withdraw at any time during the study without penalty or loss of benefits or rights to which you might otherwise be entitled. Your consent form will be kept separate from the data records to ensure confidentiality. Data will be stored electronically on a password protected folder in a shared drive through Shippensburg University. Only the principal investigators will have access to this folder. Devises used to access the electronic data in the shared folder will have an automatic logout feature after being idle for five minutes. In accordance with federal policy, data will be maintained for three (3) years. You may request a copy of the completed research report following its approval by the Center for Rural Pennsylvania.

Risks and Benefits -- Some possible negative effects might be that this study may bring on past pains and memories of experiences when discussing dementia, dementia care, and access to services. If you experience a negative emotional reaction, distress, or a traumatic episode, the researchers will provide you with contact information for mental health resources. If you have any questions about this study, please ask them now or anytime throughout the study by contacting the Project Director (dpbourassa@ship.edu), the Co-Principal Investigator (sagrov@ship.edu) or caregivingstudy@ship.edu. If you have questions pertaining to your rights as a research participant or to report objections to this study, you should contact: Dr. Matthew

Ramsey, Institutional Review Board Chairperson, Department of Communication Studies, Shippensburg University, 1871 Old Main Drive, Shippensburg, Pennsylvania 17257, 717-477-1563, mcramsey@ship.edu.

By clicking "Yes," I agree that I am at least eighteen (18) years of age and that I have voluntarily agreed to participate in this research.
Yes [RADIO BUTTON FOR SELECTION]

Please state your current job title. [TEXT BOX FOR RESPONSE]

How long have you held this position? [RADIO BUTTON FOR SELECTION]
Less than six months
Six months to one year
Between one and three years
Between three and five years
More than five years

In what county do you primarily work? [TEXT BOX FOR RESPONSE]

What are your perceptions of service provision for people with Alzheimer's disease or a related disorder in your county? [RADIO BUTTON FOR SELECTION]
Extremely poor
Poor
Neutral
Good
Very good

What training did you receive to work with people with Alzheimer's disease or a related disorder? [Please check all that apply.] [RADIO BUTTON FOR SELECTION]
Training from the county Area Agency on Aging
Training from the state Department of Aging
Training from the Alzheimer's Association
Training from Dementia Friends
Training from previous direct care work
Other [INSERTED SKIP LOGIC]

If you replied "Other" to the previous question, please provide a short explanation to help us. [TEXT BOX FOR RESPONSE]

Do you think that family caregivers have adequate information and training to care for individuals with Alzheimer's disease or a related disorder? [RADIO BUTTON FOR SELECTION]
Yes
No [INSERTED SKIP LOGIC]
I have no opinion.

What additional information or training do you think family caregivers need? Please be as specific as possible. [TEXT BOX FOR RESPONSE]

Which of the following do you see as major issues for paid caregivers/home health aides in your county? [Please check all that apply.] [RADIO BUTTON FOR SELECTION]

- Poor pay
- Lack of transportation
- Lack of child care
- Lack of benefits
- The rural location of the county
- Other employment opportunities
- Lack of experience working with people with Alzheimer's disease or a related disorder
- Other [INSERTED SKIP LOGIC]

If you replied "Other" to the previous question, please provide a short explanation to help us. [TEXT BOX FOR RESPONSE]

If finances were endless, what types of programs or services would you like to see created to help individuals with Alzheimer's disease or a related disorder and their caregivers? Please be creative! [TEXT BOX FOR RESPONSE]

Survey of Home Health Care Aides
Administered through Qualtrics
Data Collected September 27, 2023 through November 21, 2023
Data File: Excel – Home Health Care Aides Raw Data from Qualtrics

Thank you for visiting our link to the project: "Caring for Pennsylvanians with Dementia and Related Disorders: An Analysis of Needs and Capacity in Rural Areas, 2024-2034." This project has been approved by the Shippensburg University Institutional Review Board (IRB) which requires that we provide the following disclosures associated with this project.

Please read the Informed Consent document below. After reviewing the document, click on "Yes" to start the survey. Clicking on the link notes that you have read and understood the scope of this project. If you have any questions, please contact us at caregivingstudy@ship.edu. Informed Consent Project Director Co-Principal Investigator Dr. Dara Bourassa, Professor, Department of Social Work and Gerontology, Shippensburg University, 1871 Old Main Drive, Shippensburg, Pennsylvania 17257, 717-477-1969, dpbourassa@ship.edu Project Director Co-Principal Investigator Dr. Sara Grove, Professor Emeritus, Department of Political Science, Shippensburg University, 1871 Old Main Drive, Shippensburg, Pennsylvania 17257, 717-477-1718, sagrov@ship.edu.

Informed Consent

Purpose -- The purpose of this qualitative research project is to develop a comprehensive assessment of dementia care in Pennsylvania from 2010 to 2034, identify any potential gaps existing in the network that is providing dementia care in Pennsylvania from 2023 through 2034, and to identify innovative programs that exist to address the needs of individuals with Alzheimer's Disease and Related Disorders (ADRD) and their caregivers. As part of this study, you will be asked a series of multiple choice and open-ended questions.

Participant's Rights -- Your participation in this project is voluntary. You may skip any questions that you do not wish to answer or complete. You may choose not to participate or withdraw at any time during the study without penalty or loss of benefits or rights to which you might otherwise be entitled. Your consent form will be kept separate from the data records to ensure confidentiality. Data will be stored electronically on a password protected folder in a shared drive through Shippensburg University. Only the principal investigators will have access to this folder. Devises used to access the electronic data in the shared folder will have an automatic logout feature after being idle for five minutes. In accordance with federal policy, data will be maintained for three (3) years. You may request a copy of the completed research report following its approval by the Center for Rural Pennsylvania.

Risks and Benefits -- Some possible negative effects might be that this study may bring on past pains and memories of experiences when discussing dementia, dementia care, and access to services. If you experience a negative emotional reaction, distress, or a traumatic episode, the researchers will provide you with contact information for mental health resources. If you have any questions about this study, please ask them now or anytime throughout the study by contacting the Project Director (dpbourassa@ship.edu), the Co-Principal Investigator (sagrov@ship.edu) or caregivingstudy@ship.edu. If you have questions pertaining to your rights as a research participant or to report objections to this study, you should contact: Dr. Matthew

Ramsey, Institutional Review Board Chairperson, Department of Communication Studies, Shippensburg University, 1871 Old Main Drive, Shippensburg, Pennsylvania 17257, 717-477-1563, mcramsey@ship.edu.

By clicking "Yes," I agree that I am at least eighteen (18) years of age and that I have voluntarily agreed to participate in this research.
- Yes [RADIO BUTTON FOR SELECTION]

Please state your current job title. [TEXT BOX FOR RESPONSE]

How long have you held this position? [RADIO BUTTON FOR SELECTION]
- Less than six months
- Six months to one year
- Between one and three years
- Between three and five years
- More than five years

In what county do you primarily work? [TEXT BOX FOR RESPONSE]

What are your perceptions of service provision for people with Alzheimer's disease or a related disorder in your county? [RADIO BUTTON FOR SELECTION]
- Extremely poor
- Poor
- Neutral
- Good
- Very good

What training did you receive to work with people with Alzheimer's disease or a related disorder? [Please check all that apply.] [RADIO BUTTON FOR SELECTION]
- Training from the county Area Agency on Aging
- Training from the state Department of Aging
- Training from the Alzheimer's Association
- Training from Dementia Friends
- Training from previous direct care work
- Other [INSERTED SKIP LOGIC]

If you replied "Other" to the previous question, please provide a short explanation to help us. [TEXT BOX FOR RESPONSE]

Do you think that family caregivers have adequate information and training to care for individuals with Alzheimer's disease or a related disorder? [RADIO BUTTON FOR SELECTION]
- Yes
- No [INSERTED SKIP LOGIC]
- I have no opinion.

What additional information or training do you think family caregivers need? Please be as specific as possible. [TEXT BOX FOR RESPONSE]

Which of the following do you see as major issues for paid caregivers/home health aides in your county? [Please check all that apply.] [RADIO BUTTON FOR SELECTION]

- Poor pay
- Lack of transportation
- Lack of child care
- Lack of benefits
- The rural location of the county
- Other employment opportunities
- Lack of experience working with people with Alzheimer's disease or a related disorder
- Other [INSERTED SKIP LOGIC]

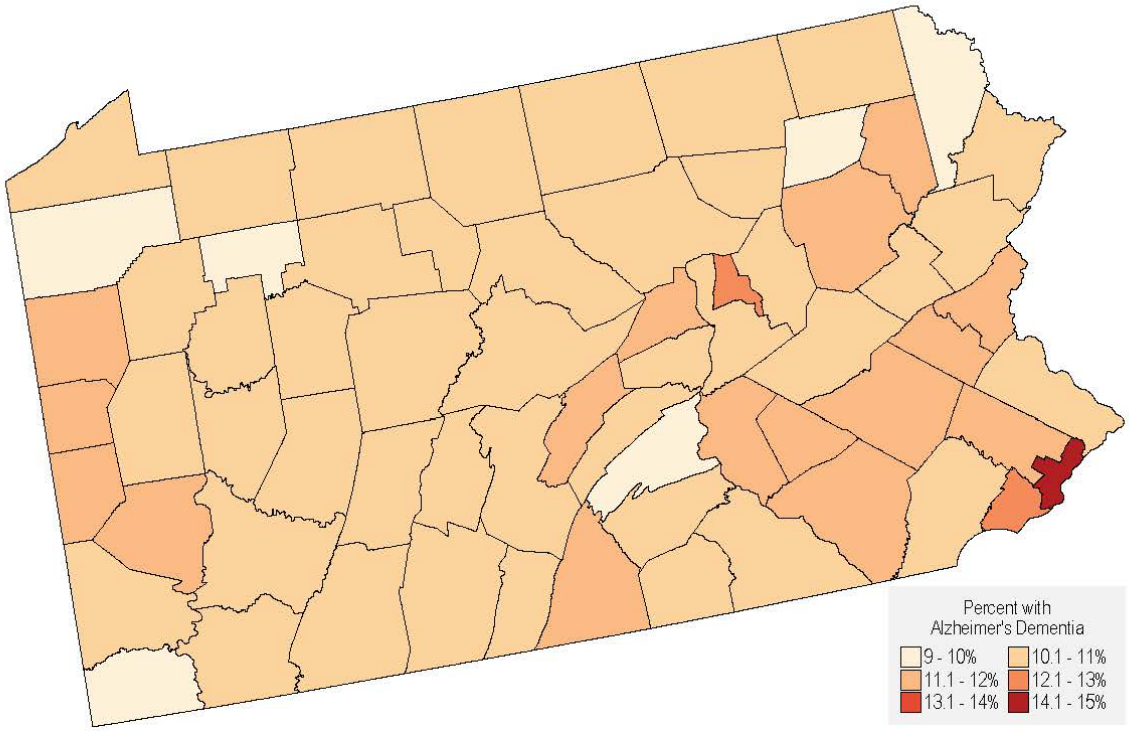
If you replied "Other" to the previous question, please provide a short explanation to help us. [TEXT BOX FOR RESPONSE]

If finances were endless, what types of programs or services would you like to see created to help individuals with Alzheimer's disease or a related disorder and their caregivers? Please be creative! [TEXT BOX FOR RESPONSE]

Appendix 2: Map of Alzheimer's Dementia Rates in Pennsylvania (Age 65+) and Prevalence Estimates by County

Appendix 2
Alzheimer's Dementia in Pennsylvania (Age 65+)

Reprinted with permission from the Alzheimer's Association of Pennsylvania (2024)



Based on data from: Dhana et al., Alzheimer's & Dementia, 2023

State	County	Alzheimer's Dementia Prevalence Estimates, 2020		
		Total Pop. Age 65+ (nearest 100)	AD Cases Age 65+ (nearest 100)	AD Prevalence (Age 65+)
Pennsylvania		2,447,700	282,100	11.5%
Columns C & D are estimates that have been rounded to the nearest 100 and are not the exact figures used to calculate AD prevalence in column E. *State totals were independently modeled (and may not equal a sum of all rounded counties)* *Source: Dhana et al., Alzheimer's & Dementia, 2023*	Adams	22,100	2,300	10.4%
	Allegheny	239,800	28,500	11.9%
	Armstrong	14,900	1,600	10.6%
	Beaver	36,500	4,100	11.2%
	Bedford	11,500	1,300	11.0%
	Berks	75,700	8,600	11.4%
	Blair	26,200	2,900	11.0%
	Bradford	13,500	1,400	10.5%
	Bucks	124,700	13,600	10.9%
	Butler	37,900	4,000	10.6%
	Cambria	30,500	3,400	11.0%
	Cameron	1,300	100	10.6%
	Carbon	14,200	1,500	10.2%
	Centre	25,000	2,600	10.6%
	Chester	91,200	9,900	10.8%
	Clarion	7,900	800	10.5%
	Clearfield	16,800	1,800	10.9%
	Clinton	7,500	800	10.7%
	Columbia	13,200	1,400	10.7%
	Crawford	18,300	1,800	9.9%
	Cumberland	49,200	5,400	10.9%
	Dauphin	49,800	5,800	11.6%
	Delaware	97,900	12,000	12.3%
	Elk	6,800	700	10.9%
	Erie	51,500	5,600	10.8%
	Fayette	28,600	3,100	10.8%
	Forest	1,700	200	9.5%
	Franklin	31,700	3,500	11.1%
	Fulton	3,200	300	10.1%
	Greene	7,100	700	9.9%
	Huntingdon	9,700	1,000	10.4%
	Indiana	17,200	1,800	10.4%
	Jefferson	9,400	1,000	10.8%
	Juniata	5,200	600	10.9%
	Lackawanna	43,100	4,800	11.2%
	Lancaster	103,600	11,900	11.5%
	Lawrence	19,500	2,200	11.3%
	Lebanon	28,500	3,200	11.2%
	Lehigh	64,400	7,400	11.4%
	Luzerne	64,500	7,200	11.2%
	Lycoming	23,000	2,500	10.9%
	McKean	8,200	900	10.7%
	Mercer	24,800	2,800	11.5%
	Mifflin	10,200	1,100	11.2%

	Monroe	31,500	3,300	10.6%
	Montgomery	154,700	18,400	11.9%
	Montour	4,000	500	12.2%
	Northampton	61,100	7,000	11.5%
	Northumberland	20,000	2,200	11.0%
	Perry	9,100	900	9.5%
	Philadelphia	227,000	34,000	15.0%
	Pike	13,500	1,400	10.3%
	Potter	4,100	400	10.7%
	Schuylkill	29,800	3,200	10.7%
	Snyder	8,000	900	11.0%
	Somerset	17,100	1,900	10.9%
	Sullivan	1,800	200	10.3%
	Susquehanna	9,900	1,000	10.2%
	Tioga	9,300	1,000	10.4%
	Union	8,400	1,000	11.8%
	Venango	12,100	1,300	10.4%
	Warren	9,400	1,000	10.5%
	Washington	44,500	4,800	10.7%
	Wayne	12,800	1,300	9.9%
	Westmoreland	82,700	8,900	10.8%
	Wyoming	6,000	600	9.7%
	York	83,100	8,900	10.7%

Appendix 2: Organizational Stakeholders and Their Advocacy Organizations

Individual(s) Interviewed	Organization
Jason Kavulich Karen Gray (in attendance)	Pennsylvania Department of Aging
Sara Murphy	Alzheimer's Association
Karen Leonovich	Pennsylvania Association of Area Agencies on Aging (P4A)
Jennifer Brush Mandy Cheskis	Montessori for Dementia and Aging Program
Haylie Gruntz Anna Hykes	SpiriTrust Lutheran LIFE Program
Zach Shamberg	Pennsylvania Health Care Association
Kristin Daughtery	Steinbacher, Goodall & Yurchak Elder Law Firm
Katie Dotto	Pennsylvania Homecare Association
C.J. Weaber	Honor Health Network (Angels on Call)
Ed Polakowski	Former Home Health Care Agency Owner
Madison Hurley	Albright LIFE
Joann Decker	Regional Manager (Angels on Call)

Appendix 3: Innovative Programs and Services

AARP Network of Age-Friendly States and Communities
WEBSITE: https://www.aarp.org/livable-communities/network-age-friendly-communities/
SUMMARY: Community-oriented programs to promote healthy aging
FUNDING SOURCE: Private

ACT on Alzheimer's
WEBSITE: http://www.actonalz.org
SUMMARY: Minnesota statewide initiative that uses the Dementia Friends Model
FUNDING SOURCE: Private

Benjamin Rose Institute on Aging and Family Caregiving Alliance
WEBSITE: https://bpc.caregiver.org/#searchPrograms
SUMMARY: Online database for family caregivers
FUNDING SOURCE: Private

Centers for Disease Control
WEBSITE: https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf
SUMMARY: Public health initiatives providing educational resources related to dementia
FUNDING SOURCE: Federal government

Dementia Friends USA
WEBSITE: https://dementiafriendsusa.org
SUMMARY: Community-oriented programs to educate individuals about dementia and to assist with care for individuals living with dementia
FUNDING SOURCE: Private

Java Group Programs
WEBSITE: https://javagp.com
SUMMARY: Peer support interventions, including music, memory care, and mentorship
FUNDING SOURCE: Private

Maryland Community for Life
WEBSITE: https://communityforlifemd.com
SUMMARY: Provides home maintenance, service navigation, and transportation
FUNDING SOURCE: Membership fees paid by individuals

Maryland Department of Health, Maryland Faith Health Network, and Maryland Volunteer Lawyers Service
WEBSITES: https://mvlslaw.org and https://www.mhaonline.org
SUMMARY: Community partnership to promote advanced care planning for individuals with cognitive impairment
FUNDING SOURCE: State and Private

Maryland Durable Medical Equipment Re-Use Program
WEBSITE: https://aging.maryland.gov/pages/DME.aspx
SUMMARY: Provides durable medical equipment to Marylanders with any illness, injury, or disability, regardless of age, at no cost; all equipment is collected via donation, sanitized, repaired, and redistributed to Marylanders in need.
FUNDING SOURCE: State and Donation

Massachusetts Engaging with Employers to Support Family Caregivers
WEBSITE: Currently disabled
SUMMARY: Partnership with the Massachusetts Business Roundtable to engage employers in developing policies to support family caregivers in the workplace
FUNDING SOURCE: Private

Memory Cafes
WEBSITE: https://wai.wisc.edu/wp-content/uploads/sites/1129/2020/04/memorycafeguide.pdf
SUMMARY: Based on a program from the United Kingdom, creates a ninety-minute dementia-friendly outing for individuals living with ADRD and their caregivers
FUNDING SOURCE: Private

Maximizing Independence at Home (MIND at Home™) Program
WEBSITES: http://www.mindathome.org and
https://www.hopkinsmedicine.org/news/articles/mind-at-home
SUMMARY: Home-based care coordination program supported by Johns Hopkins University
FUNDING SOURCE: Private

Mississippi Brain Aging Research Alliance (BARA)
WEBSITE: https://portal.alzimpact.org/uploads/media/state_plans/MS.pdf/
SUMMARY: Part of the Mississippi State Plan on Aging
FUNDING SOURCE: State

Money Follows to Person (MFP) Initiative
WEBSITE: https://www.medicaidplanningassistance.org/money-follows-person/
SUMMARY: Medicaid program that provides financial assistance for individuals to leave skilled nursing facilities and return home
FUNDING SOURCE: State

Montessori for Dementia and Aging
WEBSITE: https://montessoridementia.org
SUMMARY: Training (synchronous or asynchronous) to promote the use of the Montessori philosophy to care for individuals living with dementia
FUNDING SOURCE: Fee paid by individuals for twelve-hour online course ($199)

Washington Department of Social and Health Services
WEBSITE: https://www.dshs.wa.gov/
SUMMARY: Promotes consistent and extensive training for long-term care workers (seventy hours), including specific training on dementia
FUNDING SOURCES: State

The Wright Center
WEBSITE: https://thewrightcenter.org/services/alzheimers-dementia/
SUMMARY: Serves individuals living with dementia and their caregivers in northeast Pennsylvania through a range of health and supportive services; it is based on the Alzheimer's and Dementia Care Program at UCLA (https://www.uclahealth.org/dementia/)
FUNDING: Private insurance

Appendix 5: State Programs Permitting Spouses to Receive Compensation as Caregivers

State	Program
Alabama	Alabama Community Transition (ACT) Medicaid Waiver
Arizona	Self-Directed Attendant Care (SDAC)
California	In Home Supportive Services (IHSS)
Colorado	Consumer Directed Attendant Support Services (CDASS) Program
Delaware	Diamond State Health Plan – Plus
Florida	Statewide Medicaid Managed Care Long-Term Care Program
Hawaii	Med-QUEST
Indiana	Indiana Aged and Disabled Medicaid Waiver / CDAC Program
Kentucky	Hart Supported Living Program Home and Community Based Services Waiver for Aged and Disabled
Louisiana	Community Choices Waiver
Maryland	Maryland Community Personal Assistance Services
Minnesota	Alternative Care Program Elderly Waiver Consumer Support Grant Program
Montana	Big Sky / Home and Community Based Services Waiver
New Hampshire	CHOICES
New Jersey	Medicaid Managed Long Term Services and Support and New Jersey Assistance for Community Caregivers
New Mexico	New Mexico Centennial Care Community Benefit
North Carolina	In-Home Aide Program
State	**Program**
North Dakota	Aged and Disabled Waiver (Family Personal Care)
Oklahoma	Advantage Program
Oregon	Spousal Pay Program, Independent Choices Program, and K Plan / Community First Choice
Utah	Utah Medicaid Aging Waiver
Vermont	Global Commitment to Health Waiver
Wisconsin	Wisconsin Family Care and Family Care Partnership Program

Source: Paying for Senior Care, 2023, accessed at: https://payingforseniorcare.com/paying-spousal-caregivers.

Center for Rural Pennsylvania Board of Directors

Center for Rural Pennsylvania Staff

625 Forster St., Room 902, Harrisburg, PA 17120
(717) 787-9555 | www.rural.pa.gov