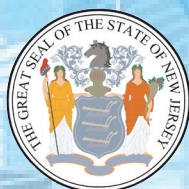


New Jersey Alzheimer's Disease Study Commission

Report

Submitted to the Governor and the Legislature

August 2016



The New Jersey Alzheimer's Disease Study Commission, created by Public Law 2011, chapter 76, was mandated to study the current issues in New Jersey associated with Alzheimer's disease and comprehensively assess the needs of the State's infrastructure and residents with regard to the disease's impact. Public Law 2011, chapter 76 will expire upon the submission of this report to the Governor and the Legislature.

Table of Contents

Purpose of the Commission.....	3
Members.....	4
I. Commission Activities.....	5
A. Information and Research	
B. Listening Sessions	
C. Web-based Survey	
II. Alzheimer’s Disease: A Definition.....	12
III. Alzheimer's Disease: Impact and Trends	
A. Demographics.....	15
1. Down Syndrome and Alzheimer’s Disease	
2. Early-onset Alzheimer’s Disease and Other Dementias	
B. Family Impact.....	19
C. Community Impact.....	24
1. Caregiver Health	
2. Impact on Children	
D. Workforce Impact.....	25
E. Financial Impact.....	28
F. Impact on the State’s Medical Infrastructure.....	31
1. Hospitals	
2. Nursing Homes	
3. Geriatric Mental Health	
4. Healthcare in the Community	
5. Physicians	
6. End of Life	
7. Medical Research	
8. Training of New Jersey’s Healthcare Workforce	

G.	Impact on the State’s Community Resources.....	40
	1. Focus Area: Managed Long Term Services and Supports	
	2. Focus Area: Down Syndrome	
	3. Focus Area: Fraud, Abuse, and Neglect	
	4. Focus Area: Person-centered Care	
H.	Public Safety Impact.....	46
	1. Wandering and Elopement	
	2. Driving and Car Access	
	3. First Responders	
	4. Disaster Preparedness	
IV.	Recommendations by the Commission.....	51
	1. Goal 1: Increase public awareness of the difference between “normal” cognitive aging and Alzheimer's disease and related dementias.	
	2. Goal 2: Expand support for unpaid caregivers of persons with Alzheimer's disease.	
	3. Goal 3: Promote the infrastructure for enhanced quality of services within the healthcare system to meet the growing number of people with Alzheimer's disease.	
	4. Goal 4: Improve public safety and address the safety-related needs of those with Alzheimer's disease living in the community.	
	5. Goal 5: Support legal protections for, and legal issues faced by, individuals with Alzheimer's disease.	
V.	Appendices.....	59
	A. Appendix A: Sample Survey Question	
	B. Appendix C: Demographics	

Purpose of the Commission

The New Jersey Alzheimer's Disease Study Commission, created by Public Law 2011, chapter 76, was mandated to study the current issues in New Jersey associated with Alzheimer's disease and to comprehensively assess the needs of residents related to the state infrastructure of services for the disease. Public Law 2011, chapter 76 will expire upon the submission of this report to the Governor and the Legislature. This legislation was sponsored by Senators Christopher J. Connors and Jeff Van Drew; and Assembly members Brian E. Rumpf, Matthew W. Milam, Nelson T. Albano, Valerie Vainieri Huttie, and Herb Conaway, Jr. and signed into law by Governor Chris Christie on June 21, 2011.

Specific activities were required of the Commission:

- a) Study the current impact and incidence of Alzheimer's disease among state residents, and make projections about the future impact and incidence among state residents;
- b) Study the State's role in long-term care, family caregiver support, and assistance to persons with early stage and early onset of Alzheimer's disease;
- c) Consider the capacity of public safety and law enforcement officials to respond to persons with Alzheimer's disease and for these officials to have proper education and training;
- d) Study the needs of persons with Alzheimer's disease and their family members and caregivers, assess the availability and affordability of existing services, programs, facilities, and agencies to meet those needs, and make recommendations for improving, expanding, or changing such services, programs, facilities, and agencies, as appropriate;
- e) Gather and disseminate data and information relative to the care of persons with Alzheimer's disease in order to provide health care professionals and governmental policymakers, as appropriate, with accurate data about the disease and its impact on these persons and their family members and caregivers;
- f) Identify the adequacy, appropriateness, and best practice-based geriatric and psychiatric services and interventions; and
- g) Consider such other issues as the Commission may identify as necessary to ease the burden for persons with Alzheimer's disease and their family members and caregivers in the state.

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Commission Activities

To enhance, centralize and advance the alignment of aging services in New Jersey, Governor Chris Christie transferred senior services from the Department of Health and Senior Services to the Department of Human Services (DHS), in July 2012. This included the NJ Alzheimer's Disease Study Commission (Commission), which was created by Public Law 2011, chapter 76. The Commission had a full complement of members in June 2013, and began meeting that fall.

Since then, staff support to the Commission has been provided by the DHS Division of Aging Services under the purview of the Deputy Commissioner, who also served as the Department's ex-officio representative and its chair to the Commission. The Commission also elected Dr. Steven Scheinthal, DO, DFACN, DFAPA to serve as co-chair.

Since the Commission began meeting, specific activities have been undertaken in support of this report by exploring the current impact of Alzheimer's disease in New Jersey and by making recommendations for the state to take. Major focus areas included the (1) collection of research and information specific to Alzheimer's disease and New Jersey, (2) the holding of statewide listening sessions, and (3) the dissemination of a web-based survey to the general public.

Information and Research

At the outset, given the vast literature on the topic of Alzheimer's disease, the Commission started its own fact finding and research gathering mission. Subcommittees were created based on major topics, which included education, awareness and training, public safety, and health care infrastructure. The information gained from these subcommittees helped to provide the foundation for the context of the report and represents the collective expertise of the Commission members with their diverse interests and knowledge base.

The education, awareness and training subcommittee studied issues relating to the above-mentioned areas and reported its findings to the Commission. Among its tasks was a review of the current resources available in New Jersey. The subcommittee categorized existing services and reached out to a variety of community sources to determine the availability of services. Such organizations included the Office of Emergency Management, the Area Agencies on Aging (AAAs), the United Way, academia, faith-based organizations and healthcare professional networks, among others.

Listening Sessions

In order for stakeholders and the public to share ideas and perspectives about what should be included in this report, the Commission held a series of listening sessions around the state. These forums served to secure local input on the needs and concerns of individuals with Alzheimer's disease and their families. The public also was invited to provide written testimony - about 30 comments were submitted.

The formal sessions were held in 2014 on Thursday, November 13 in Galloway, November 20 in Glassboro, and December 4 in New Brunswick. A total of approximately 100 individuals including many caregivers attended the sessions to provide input. The following common themes were emphasized: the need for New Jersey to increase awareness about Alzheimer's disease and reducing its stigma; the need for a healthcare workforce trained in caring for patients with the disease; the importance of family members as caregivers; public safety concerns; the financial challenges of caring for someone with Alzheimer's disease; and the importance of increased research funding to promote a cure and treatment.

With regard to increasing public awareness and reducing the stigma associated with Alzheimer's disease, there were a range of comments offered. Here is an overview of the needs and concerns that were raised in terms of messaging through increased public awareness and education:

- There must be increased public awareness about Alzheimer's disease throughout all sectors of society, from the general public to the healthcare community;
- Early warning signs for Alzheimer's disease need to be promoted and acknowledged;
- Other dementias exist besides Alzheimer's disease;
- Public education around the myths;
- Importance of self-direction after diagnosis for the individual with Alzheimer's disease;
- Wellness Medicare visits need to be encouraged, including the cognitive impairment assessment;
- An understanding of the behavior of a person with dementia with regard to being non-compliant and acting out in public;
- While Alzheimer's disease may be an older person's problem, it affects all generations as the young can also be affected when a grandparent or other family member becomes ill with it;
- Children and teenagers need to be educated about dementia as they often notice subtle changes in the family members early on in the disease progression;
- Alzheimer's disease and related disorders should be viewed apart from mental health issues; and
- Primary caregivers often meet with resistance when attempting to confirm a diagnosis and move ahead with care for a loved one with dementia because society is not attuned to the signs, symptoms and progression of Alzheimer's disease and related dementias.

Another recurrent theme in the oral testimony revolved around the coordination and delivery of care by the healthcare community: hospital systems, long-term care services, community services, emergency medical services, and other medical and mental health providers. Among the common subjects raised were the following:

- Incentives, ranging from special internships to school loan forgiveness, are desirable to encourage healthcare professionals to enter the field of geriatrics with a specialty in dementia;
- Increased residential housing options are important for persons with dementia who have challenging behaviors to manage, such as combativeness or agitation;
- Education of physicians so that they give newly diagnosed patients the appropriate information about dementia, and the available resources and support programs;
- Direct care workforce training in hospitals so the entire hospital system is better equipped to deal with dementia-related behaviors;
- Understanding, acknowledging and taking action related to the extra layer of complexity in discharging those affected from hospitals and nursing facilities;
- Care for persons with dementia is best managed by an interdisciplinary team to provide coordinated, all-inclusive care; and
- Focus on medical schools and the education of geriatricians and geriatric psychiatrists.

Since the impact of Alzheimer's disease is experienced intensely by family caregivers, the topic of empowering caregivers emerged as a theme at all three listening sessions. The following issues were raised by those who provided testimony:

- Heavy burden of care is taken on by caregivers in the managing of the daily concerns of persons with Alzheimer's disease and other dementias;
- Support for the entire family is important through all phases of the disease process;
- Education is invaluable for caregivers so they can learn about all the possible resources during what is a very stressful period for them;
- Resources for caregivers need to be easily researchable and publicized, and the existence of a central dementia care website with New Jersey-specific information would be useful;
- Respite care services and adult day care services are essential options in terms of providing breaks for family caregivers and enabling them to continue caring for loved ones at home;
- Fear of having to place a loved one with Alzheimer's in a nursing home when caregiving at home is no longer possible; and

- Recognition that “sundown syndrome” is an additional issue that can add to the challenges of caregiving for someone with Alzheimer’s disease and other dementias.¹

Ensuring public safety for persons with Alzheimer’s disease and other dementias was raised as a topic throughout the public input sessions and highlighted these particular issues:

- Exploration of an age-related test of driving skills should be considered to determine when it is no longer safe for a person to drive. The test may also be a means of identifying cognitive changes early in the process;
- Importance of training for police and responders in dementia-related behaviors. Without the proper training, a first responder on an emergency call could mistakenly attribute the person’s behavior to mental illness or other condition; and
- More effective usage of telephone “do not call” lists so persons with dementia are not taken advantage of over the phone.

A number of individuals providing testimony touched on the financial issues associated with Alzheimer’s disease and other dementias, including the following:

- Middle class families are more economically disadvantaged when it comes to being able to access services and supports that are only available for lower income groups; and
- The Medicaid slots in assisted living residences are often filled by private pay residents who have spent down their resources and so are unavailable to Medicaid-eligible individuals living in the community.

In addition, the DHS received written input from about 30 individuals who reiterated many of the aforementioned issues in addition to the following comments:

- Many primary care providers in the community are ill-prepared to identify, diagnose, or treat dementia. They may not be open to exploring the issue with patients, or with talking with families about the signs they see at home;
- The ongoing, seemingly unending grind of daily Alzheimer’s care and the lack of recognition of this reality by the medical community, social services, and other “supports;”
- The burden of what it takes to get help: applications, verifications, repeat appointments, and denials;
- The added problems of early-onset Alzheimer’s, especially financial;

¹ Sundowning is characterized by changes in how an individual with dementia acts in the late afternoon or early evening. Common behavior changes can include sleeplessness (possibly all night), agitation, wandering, and aggression. Effectively managing sundowning involves multiple services and disciplines in tight coordination.

- While Alzheimer's disease may be an older person's problem, it affects all generations as the young can also be affected when a grandparent or other family member becomes ill with it; and
- Fear of having to place a loved one with Alzheimer's in a nursing home when caring for them at home is no longer possible.

The New Jersey Association of Area Agencies on Aging (NJ4A), which represents the 21 offices on aging or Area Agencies on Aging (AAAs), also submitted written testimony. A function of county government, funded with county, state, and federal funds (largely through the Older Americans Act), the AAAs are a resource for community-dwelling seniors and adults living with disabilities. The AAAs serve the person receiving care and the family caregiver, who also may be a senior; 19% of family caregivers are over age 65.²

NJ4A's membership made the following recommendations:

- Respite opportunities need to be readily available and be offered at non-traditional times to include drop-in day care and longer day care hours.
- Education for the professional and para-professional should be enhanced to include strategies for improved communication and deal with challenging behaviors.
- Concentrated and tailored caregiver education related to the type of dementia needs to improve when a diagnosis is made.

NJ4A also mentioned programs offered by two of their member AAAs as examples that potentially could be replicated statewide. These will be discussed in the section of this report on community resources.

Web-Based Survey

The New Jersey Alzheimer's Disease Study Commission, through its Education/Awareness/Training sub-committee, created an online survey. It was disseminated to gather input from New Jersey residents affected by Alzheimer's and related disorders, including caregivers and providers. The Stockton Center on Successful Aging (SCOSA) at Stockton University provided assistance by handling the survey design, online deployment, follow-up, and this report.

Survey Design

The Education/Awareness/Training sub-committee researched and reviewed a number of surveys that were used to help formulate other similar state plans in the United States. It was concluded that a single, brief and general survey should be created to assess opinions and needs with respect to dementia-specific topics from a diverse array of stakeholders. Questions were drafted that could be

² "Caregiving in the U.S.: 2015 Report" p. 18-20. AARP Public Policy Institute, National Alliance for Caregiving. June 2015.

answered by multiple audiences, including people with the disease, family caregivers, professional caregivers, educators, medical personnel, first responders, and others. There were also questions geared to specific target groups.

The sub-committee submitted a final draft of the survey to the Commission in November 2014. After this review, a Spanish-language version was created with assistance from Stockton University. The survey instruments and proposed survey collection methodology were submitted for and received approval from the Stockton University Institutional Review Board.

Survey Deployment and Sampling Methodology

The survey was made available via SurveyMonkey in January 2015. The survey link was distributed primarily via email. Members of the Commission, its subcommittees, and SCOSA shared the survey statewide with caregiver groups, senior citizen organizations, advocacy groups, and county Area Agencies on Aging (AAAs). The survey was also promoted on the Commission's web page. The survey remained open through June 10, 2015. Several organizations allowed respondents to use a print version of the SurveyMonkey and their written responses were then entered into the tool. Senior centers and AAAs reported assisting caregivers and people with cognitive loss with the survey as needed due to low functional literacy, low vision, difficulties in manipulating a computer mouse and keyboard, or other barriers.

Results Overview

A total of 460 surveys were completed: 457 English language and three Spanish language versions. About 4% of the respondents to the English language version identified as Hispanic. The limited response rate may not accurately represent the true picture of the population under study.

Of the respondents who provided care to spouses, friends, or family members, 43% reported spending more than 15 hours each day caregiving. Both professionals and family caregivers overwhelmingly responded that training was "very important" (86.3% and 90%, respectively). Sadly, less than half of family caregivers (42.4%) reported having received any training or education on Alzheimer's or dementia. When asked for additional detail about their past training experiences, over half (51%) of all respondents indicated that their training had met their needs. Notably, 32% of respondents indicated that caregiver and/or other duties had limited their training opportunities, and 18% indicated that the training was not comprehensive.

Specific to dementia training, the following issues were noted:

- Only half (51%) of all respondents, both professionals and family caregivers, rated their training as having met their needs;
- 18% felt the training was not comprehensive, and

- More than one-third of family caregivers (35.6%) stated that caregiving duties reduced their ability to participate in training.

In addition, 21% of caregivers reported that lack of transportation influenced their decision to use any services.

One question asked participants about the type of training and information they would like to have available. Responses clustered into two main categories. The first focused on care of the person with Alzheimer's disease: 71.36% would like additional information on resources and 65.33% desired more information on caregiver issues. In the second cluster, more information was requested about behaviors exhibited by someone with Alzheimer's disease (72.11%), and disease progression/stages (60.80%). Details on the topics requested for training and information can be found in this report's *Appendix A*.

The survey also revealed that 61.54% of professional care providers reported having information on Alzheimer's and other dementias available in the workplace.

Acknowledgements

The Commission would like to thank those involved in the creation and analysis of this survey. The survey and its analysis were prepared by Richard Jeffries, BA candidate and Intern in SCOSA at Stockton University and David Burdick, PhD, director of the Stockton Center on Successful Aging at Stockton University. The Spanish-language survey was prepared by Merydawilda Colon, PhD, executive director of the Stockton Center for Community Engagement (SCCE), Ms. Lidia Martinez, MSW candidate and Student Fellow in SCCE, and Mr. Roberto Castillo, Computer Systems Training Specialist. Commission member Linda Copping managed the subcommittee.

Alzheimer's Disease: A Definition

Alzheimer's disease is a progressive, degenerative, and irreversible neurological disease that develops over a period of years. It is one of a group of dementias referred to as "Alzheimer's disease and related disorders." Alzheimer's disease is the most common form of dementia, which is a general term for loss of memory and other cognitive abilities, serious enough to interfere with daily life. It is not a part of the "normal" aging of the brain.

It is important to note that with the release of the Diagnostic and Statistical Manual 5th Edition, which occurred during the Study Commission's information gathering phase, the term "dementia" has been replaced with the term "neurocognitive disorders." For the purpose of this report, we will maintain the use of the term dementia.

Alzheimer's disease vs. "normal" changes in cognition as the brain ages

Cognitive aging is not the same as Alzheimer's disease.

ALZHEIMER'S DISEASE	COGNITIVE AGING
Chronic neurodegenerative disease	Part of aging
Extensive neuron loss	Neuron number remains relatively stable, but neuronal function may decline
Affects approximately 10 percent of older Americans	Occurs in everyone, but the extent and nature of changes varies widely
Declines are often severe and progressive	Changes are variable and gradual

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³ "Cognitive Aging: An Action Guide for Individuals and Families." Institute of Medicine (IOM) of the National Academies of Science. Accessed July 10, 2015 at http://iom.nationalacademies.org/~media/Files/Report%20Files/2015/Cognitive_aging/Action%20Guide%20for%20Individuals%20and%20Families_V3.pdf.

Common misconceptions about cognition as the brain ages

Know the facts about cognitive aging

MISCONCEPTION	FACT
Maintaining cognitive health means preserving your memory.	Cognitive health is far more than having a good memory. It also involves decision making, attention, and problem solving.
Cognitive function always declines with age.	Aging can have both positive and negative effects on cognition. Wisdom and expertise can increase with age. Older adults experience fewer negative emotions, such as anger and worry, than people in young adulthood and middle age, and they report feeling greater satisfaction with life in general.
There's nothing you can do to improve your cognitive health.	There are actions individuals and families can take to help support their cognitive health and adapt to age-related cognitive changes. See the next page for more information.
Brain neurons die as you age, so there is no way to prevent cognitive decline.	In the absence of disease, neuron death is minimal. There are a number of actions you can take to support your cognitive health.

4

Alzheimer's disease develops slowly over a period of years and worsens over time. In its early stages, losses of executive function, such as analytical ability and reasoning, and the ability to learn or remember new information are experienced, often along with changes in sense of smell and taste, which can result in eating and nutritional problems.

The following is a description of how it is defined in the *National Plan to Address Alzheimer's Disease*:

As the disease progresses, memory continues to decline, and other functions like language skills and decision making become more difficult. Personality and behavior changes may also occur. A person with the disease may no longer recognize family and friends. Eventually, the person who survives with Alzheimer's disease is completely reliant on others for assistance with even the most basic activities of daily living, such as eating.⁵

While it may begin with gradual short-term memory loss, Alzheimer's disease progresses to include a decline in all areas of cognition, language and communication, perception and judgment, and

⁴ "Cognitive Aging: An Action Guide for Individuals and Families." Institute of Medicine (IOM) of the National Academies of Science. Accessed July 10, 2015 at http://iom.nationalacademies.org/~media/Files/Report%20Files/2015/Cognitive_aging/Action%20Guide%20for%20Individuals%20and%20Families_V3.pdf.

⁵ National Plan to Address Alzheimer's Disease, 2014 Update. Accessed 10/30/2015 at <http://aspe.hhs.gov/national-plan-address-alzheimer%E2%80%99s-disease-2014-update>.

personality. Individuals become unable to converse and be a part of their environment. The individual with AD eventually will be unable to perform the activities of daily living (ADLs) such as ambulation, dressing, feeding, and bathing.

This process takes years. It is common for an otherwise healthy person to live with Alzheimer's disease for 20 years or more. The longest period is typically the "middle stage," in which the person with Alzheimer's disease is alert and active but significantly impaired in judgment, memory, and comprehension. Hallmarks of these years are:

- Safety concerns - cooking and fire, driving, taking/not taking medication, wandering, nutrition and eating, hydration and drinking liquids;
- Health issues - managing medications, diet, recognizing pain, communicating with physicians, toileting, bathing and skin integrity;
- Financial problems - failure to pay bills, losing cash, inability to manage money on a daily basis, poor handling of assets and property, vulnerability to financial exploitation; and
- Personal care - grooming, dressing for the weather, dressing in clean clothes, shaving and hair care, brushing teeth and other oral care.

Age is the most important known risk factor for Alzheimer's disease. The older a person is, the greater the risk of Alzheimer's disease:

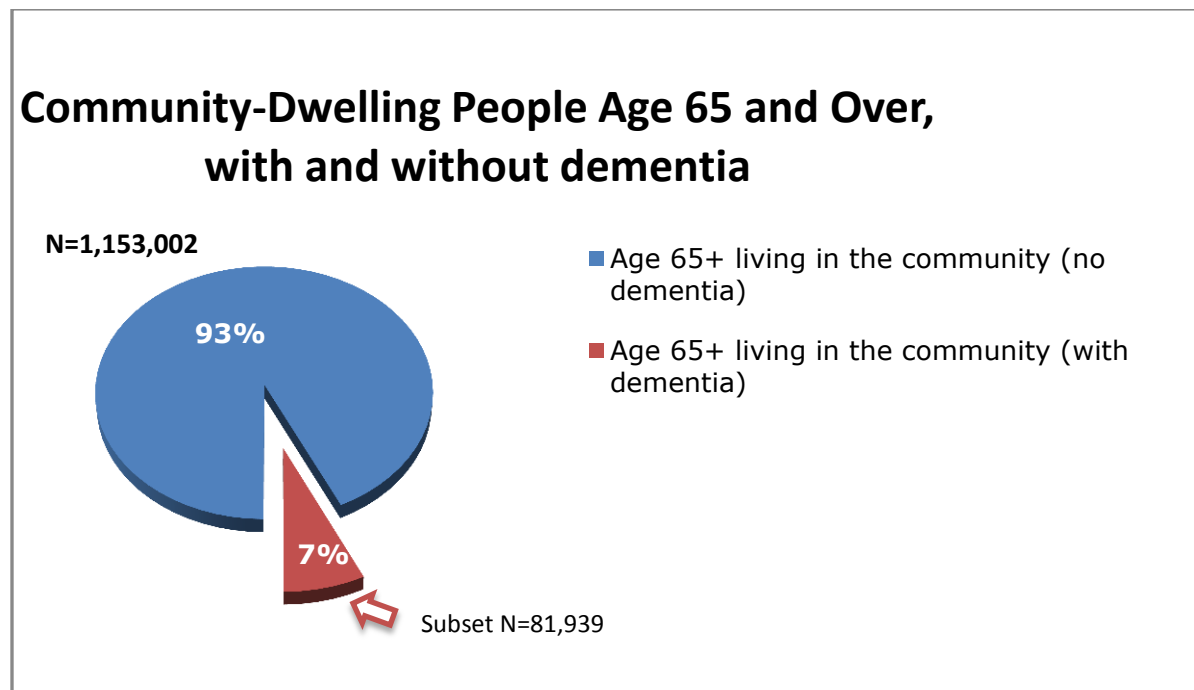
- 50% of all persons age 85 and older have Alzheimer's or another form of dementia.
- There is a small but significant group who develop early onset Alzheimer's disease; this is Alzheimer's that manifests prior to age 65. The youngest cases of early onset Alzheimer's are documented as in their early 20s.
- While there is a genetic link with early onset Alzheimer's, the Alzheimer's experienced by adults over age 65 appears to have little or no direct genetic link.
- There is scientific evidence that some of the same risk factors for heart disease and stroke are shared by people who develop Alzheimer's disease, such as high blood pressure and high cholesterol.

Diagnosis of Alzheimer's disease typically does not occur until two years after the person starts to display functional decline, such as forgetting appointments, social isolation, becoming lost, or losing common items such as keys and mail. Those with Alzheimer's disease typically live an average of eight years after diagnosis. However, survival can range from four to 20 years, depending on age and other health conditions.

Alzheimer's Disease: Impact and Trends

The Family Caregiver Alliance's 2014 *State of the State in Family Caregiving Support*⁶ identifies that New Jersey has:

- 1,186,000 New Jersey residents over age 65, and that
- 8.3% of those people age 65+ have a cognitive issue due to Alzheimer's or other dementias, stroke, etc. This means that 98,438 seniors in New Jersey had a cognitive issue, particularly dementia. Approximately 81,939 reside in the community.



Demographics

Alzheimer's disease ranks number six in the top 10 causes of death in the United States and there is no prevention or cure.⁷ The Alzheimer's Association estimates that approximately 5.3 million Americans are now living with Alzheimer's disease. Nearly one in every three older adults who dies each year has Alzheimer's disease or some kind of dementia.

⁶ State of the State in Family Caregiving Support, state profile for New Jersey. Family Caregiver Alliance. 2014. Accessed 9/2/2015 at

https://caregiver.org/sites/caregiver.org/files/pdfs/state2014/state_profile_nj_2014_final.pdf.

⁷ 2015 Alzheimer's Disease Facts and Figures. Alzheimer's Association. 2015. Available at http://www.alz.org/facts/downloads/facts_figures_2015.pdf.

The numbers are increasing: the Alzheimer's Association forecasts that by 2050 there will be as many as 16 million Americans with the disease. And these numbers are expected to continue increasing as the size and proportion of the U.S. population age 65 and older continues to grow. By 2025, for instance, the number of Americans age 65 and older with Alzheimer's disease is estimated to reach 7.1 million. By 2050, the number of Americans age 65 and older with Alzheimer's disease may nearly triple, from 5.1 million to a projected 13.8 million without major medical breakthroughs.⁸

The 2015 Alzheimer's Disease Facts and Figures report, which is produced by the Alzheimer's Association, provides statistical information on the impact of this disease in every state across the nation. Among the notable findings for New Jersey are the following:

- The projected number of New Jersey residents living with Alzheimer's disease in 2015 is 170,000 and the number is expected to climb to 210,000 by 2025, an increase of 23.5%.
- About 13% of seniors aged 65 and older are living with Alzheimer's disease.
- In 2013, the number of deaths from Alzheimer's disease was 1,812 (Source: National Center for Health Statistics).

The NJ Department of Health (DOH) currently ranks Alzheimer's disease as the seventh leading cause of death among New Jersey residents in its State Health Assessment Data (NJSHAD) System.⁹ The most recent DOH *Indicator Profile Report* was published March 19, 2015. Alzheimer's disease was listed as the eighth leading cause of death from 2004 to 2006 in New Jersey and tenth from 1998 to 2003. Before then, it was not in the top ten causes.

According to the DOH, the age-adjusted death rate due to Alzheimer's disease had been steadily increasing for several years, but decreased in 2006 before rising back up to level off at about 18 per 100,000. In New Jersey, nearly 2,000 deaths each year are due to Alzheimer's disease. In the total population and among each racial/ethnic group, females have higher death rates than males. Alzheimer's disease is the fifth leading cause of death among women and tenth among men in New Jersey. The age-adjusted death rate because of Alzheimer's disease is highest among New Jersey's white population. Alzheimer's disease is the fourth leading cause of death among persons aged 85 years and over and is surpassed only by heart disease, cancer and stroke.

In terms of racial differences, a U.S. Department of Health and Human Services (DHHS) literature review found significant variances in the incidence of Alzheimer's disease, as is highlighted below:

An analysis of 2006 Medicare claims data found that older African Americans and Hispanics were more likely than Whites to have a diagnosis of Alzheimer's disease. Rates were 14% for Hispanics, 13% for African Americans, 10% for Whites, 9% for Native Americans, and 8% for

⁸ 2015 Alzheimer's Disease Facts and Figures. Alzheimer's Association. 2015. Available at http://www.alz.org/facts/downloads/facts_figures_2015.pdf.

⁹ New Jersey State Health Assessment Data (NJSHAD) System, accessed August 2015.

Asians (Alzheimer's Association, 2011). The report's authors cautioned that prevalence rates based on diagnosis codes may reflect varying levels of under-diagnosis across populations. They also pointed out that the Health and Retirement Study has found that among those with cognitive impairment, 46% of whites over age 55 had been told by a physician that they had a memory-related disease, compared to 34% of Hispanics and 34% of African Americans.¹⁰

The DHHS review further revealed that Alzheimer's disease is commonly "mixed" with other conditions that also cause dementia, such as Lewy body disease and infarcts:

Blacks were more likely than whites to have AD mixed with other pathologies (70.7% vs 50.6%), including Lewy bodies, which are associated with hallucinations and sleep disorders (31.7% in blacks vs 24.7% in whites), and Alzheimer's plus Lewy bodies as well as infarcts (26.8% vs 2.5%).

In looking at any pathology, blacks were more likely than whites to have Lewy bodies (58.5% vs 27.2%) and infarct (43.9% vs 27.2%).

Levels of severe arteriolar sclerosis and atherosclerosis were also higher in blacks, prompting the researchers to hypothesize that black patients would be more likely to have Alzheimer's pathology combined with infarcts.¹¹

Type 2 diabetes also seems to greatly increase the risk, especially for minorities:

Among people aged 60 and above, those with type 2 diabetes have double the risk of developing dementia. Certain racial and ethnic groups in the U.S., including Latinos, African-Americans, some Asian American groups, and Native Americans, are disproportionately affected by type 2 diabetes.¹²

Additional demographics can be found in this report's *Appendix B*.

Down syndrome and Alzheimer's disease: Another demographic area of import to the nation is the high rate of Alzheimer's disease among residents with Down syndrome. The United States is home to over 400,000 people with Down syndrome. According to the organization Alzheimer's Disease International, which is the worldwide federation of associations dedicated to Alzheimer's disease:

Population studies show that the prevalence of dementia among people with ID [intellectual disabilities] appears to be about the same as in the general population...However, the

¹⁰ Racial and Ethnic Disparities in Alzheimer's Disease: A Literature Review. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health & Human Services. February 1, 2014. Available at <https://aspe.hhs.gov/report/racial-and-ethnic-disparities-alzheimers-disease-literature-review>.

¹¹ Alzheimer's Dementia Pathologies Differ by Race. Medscape Medical News. July 15, 2015. Accessed 12/7/15 at http://www.medscape.com/viewarticle/848085#vp_1.

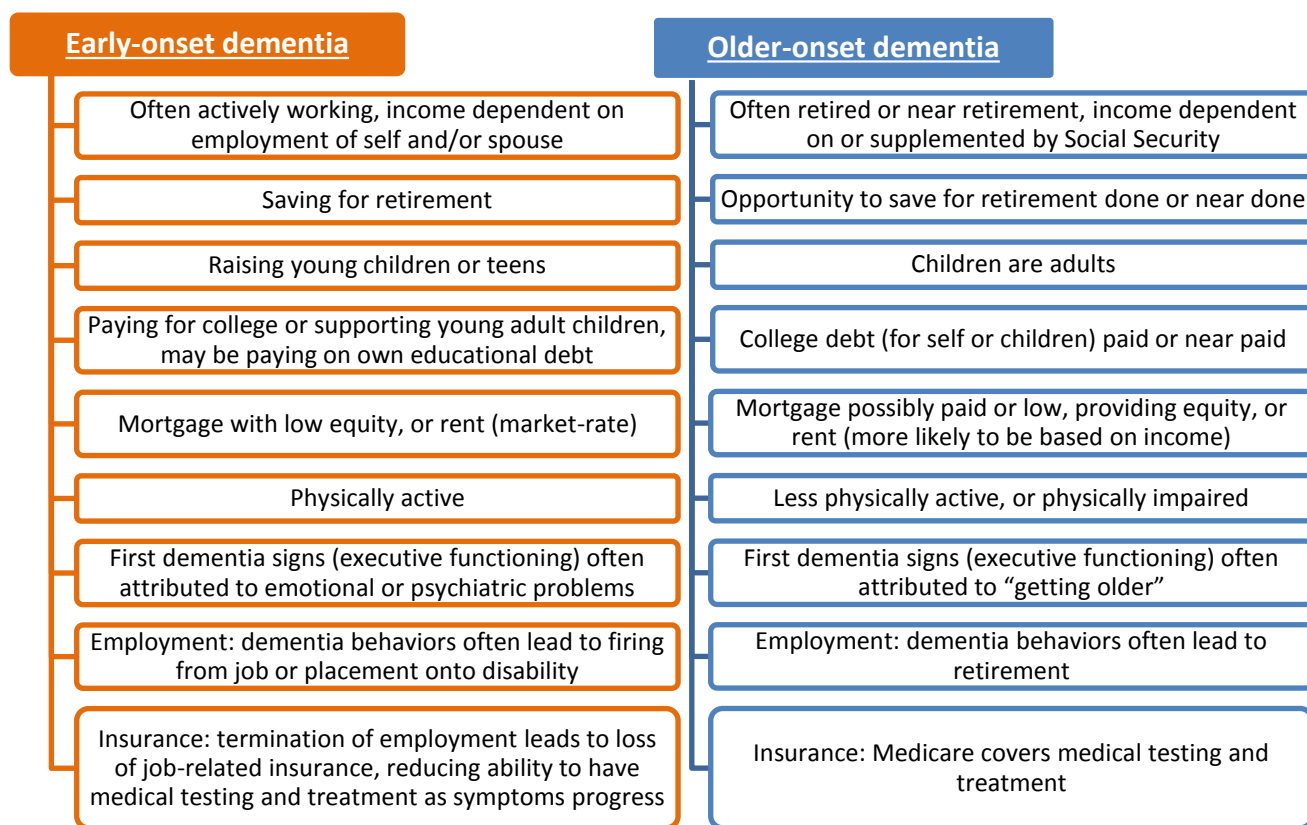
¹² Dementia Risk Greatest for Older Native Americans and African-Americans with Diabetes (press release). Kaiser Permanente. December 1, 2014. Available at <http://share.kaiserpermanente.org/article/dementia-risk-greatest-for-older-native-americans-and-african-americans-with-diabetes/>.

prevalence of Alzheimer's disease, the most common cause of dementia, among adults with Down syndrome is about 25% for those who are 40 years of age and older and about 65% for those who are 60 years of age and older.¹³

On a national level, organizations such as the National Down Syndrome Society are holding conferences, such as the June 2015 "Growing Older with Down Syndrome" conference, and providing support for caregivers of those with a combination of Down syndrome and Alzheimer's disease. Down syndrome is also a significant part of the National Plan to Address Alzheimer's Disease¹⁴.

Early-onset Alzheimer's disease and other dementias: As mentioned in the previous section of this report, dementia can strike early. While most cases of "early-onset" dementia (also called "younger-onset") are diagnosed when the person is in his/her 50s, people as young as their early 20s have been identified.

People with early-onset dementia and their families have unique challenges:



¹³ Dementia and Intellectual Disabilities. Alzheimer's Disease International. February 2003. Available at <http://www.alz.co.uk/adi/pdf/intellectualdisabilities.pdf>.

¹⁴ National Plan to Address Alzheimer's Disease, 2014 Update. Accessed 10/30/2015 at <http://aspe.hhs.gov/national-plan-address-alzheimer%E2%80%99s-disease-2014-update>.

As one spouse shared with the Commission:

Consider that no "nursing home" or similar types of facility specializes in treating EOAD [*ed.-early onset Alzheimer's disease*] sufferers. It is difficult enough to place a loved one in out-of-home care. It is even more difficult, however, when your loved one is 20-30 years younger than all of his/her fellow patients. Staff, in turn, are not used to dealing with younger, more vigorous individuals.¹⁵

Typical long-term care modalities, such as home care, adult day care, assisted living, and nursing home, are often unprepared or inappropriate for people with early-onset dementias. The strengths of a "young" person with a progressive dementia are often liabilities in these settings. These younger people are physically active and mobile, more technologically proficient, and are actively social (older adults are more likely to have smaller social circles due to withdrawal from work, loss of friends to death, etc.). The challenge for care providers, payers, diagnosticians, and even employers is to adapt for this growing group of people with dementia. The traditional method of control and physical containment (in the house, in a facility or unit) must be reassessed.

Family Impact

From the perspective of the family, the experience with Alzheimer's disease often starts with the sudden realization that "something" is wrong. One individual expressed the following in a letter to the Commission:

...this is a disease that robs the mind of its very existence, you almost want to label it a cancer of the mind without a tumor.¹⁶

It may be indicated by social withdrawal, odd behaviors, missed payments on bills, or excessive telephone calls. It may start with a traumatic fall (common in Lewy body disease) or getting lost while driving. A family may seek the opinion of a doctor, or believe that its fears are unfounded because the person's doctor has not contacted them with a diagnosis. Many families are under the misapprehension that dementia symptoms are part of normal aging.

Dad recognizes that his memory is failing but doesn't understand his physical limitations. He is unable to drive, care for himself or make financial/health decisions. Because he is a wanderer and a flight risk we've been advised that he must never be left alone. He doesn't remember that his wife died 10 years ago, or the names of his grandchildren and sometimes of his children. He often asks to speak to his grandmother who raised him and wonders why she hasn't been in touch.¹⁷

¹⁵ Letter to the Commission.

¹⁶ Letter to the Commission.

¹⁷ Letter to the Commission.

While many sources try to bring family caregiving down to a simple description (such as the “average” family caregiver as a 49 year old female caring for a parent), there is wide variety:

22% of all caregivers are caring for a person with Alzheimer's disease or another form of dementia¹⁸. There are significant differences based on ethnicity and on age. Out of all caregivers of people with Alzheimer's disease or another related disorder:

- 24% are white and caring for a person of the average age of 71.1
- 22% are African American and caring for a person of the average age of 66.3
- 25% are Asian American and caring for a person of the average age of 72.8
- 17% are Hispanic and caring for a person of the average age of 65.3

In addition, 71% of caregivers of people with Alzheimer's disease or another related disorder also state that the person has a long-term physical condition. Between dementia and the other physical ailments, caregivers report assisting with 2.2 activities of daily living (“ADLs” — eating, bathing, dressing, walking, etc.), 4.6 independent activities of daily living (“IADLs” — shopping, cooking/meal preparation, cleaning, handling money/bills, etc.), and other important tasks, such as monitoring for safety and communicating for the person.¹⁹

Many families are nearby, but their work may not be. An adult child and a person with dementia may live together, but the child may work in Manhattan — 35-65 minutes away, depending on location, traffic, or public transit. The problem is compounded if that child does not work near the major transit hubs to New Jersey and will have to negotiate travel to provide caregiving support.

Nationally, nearly half (46%) of all family caregivers provide care that, in a health care facility, would require a licensed nurse or a physician.²⁰ This care can include complex medication regimens, injections, wound care, and operating medical equipment. Of all those caregivers who perform such medical/nursing tasks as part of their caregiving, over 70% are doing this care for someone with Alzheimer's disease or another form of dementia. As part of the public input process, one letter to the Commission expressed the following caregiving scenario:

I myself am failing physically and mentally from handling my mom, the way it is going I feel I am not going to make it.²¹

¹⁸ “Caregiving in the U.S.: 2015 Report” p. 32. AARP Public Policy Institute, National Alliance for Caregiving. June 2015.

¹⁹ “Caregiving in the U.S.: 2015 Report” p. 31-32. AARP Public Policy Institute, National Alliance for Caregiving. June 2015.

²⁰ “Home Alone: Family Caregivers Providing Complex Chronic Care” p. 46. Susan C. Reinhard, Carol Levine, Sarah Samis. AARP and United Hospital Fund. September 2012.

²¹ Letter to the Commission, signed “A daughter who is dying inside trying to handle and cope.”

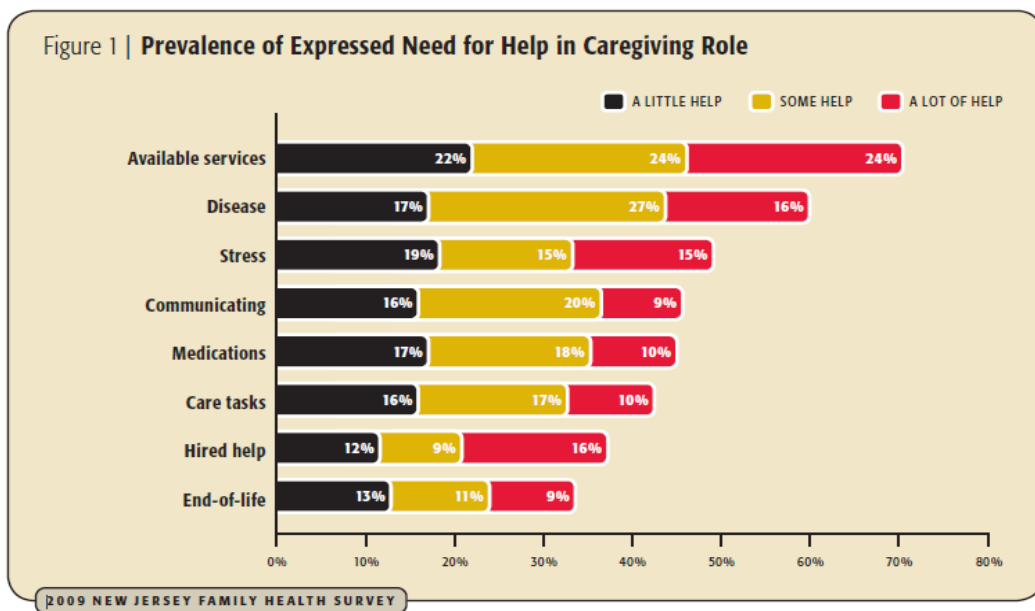
Communication is crucial. Communication can strongly influence a family's experience with dementia, no matter if the communication is with a social service agency, a physician, a hotline worker, or a local health department.

Nationally known expert Carol Levine, a former family caregiver and director of the United Hospital Fund's Families and Health Care Project (which studies family caregiving), commented:

Dementia is probably the most talked-about and written-about disease in America today. Yet when it comes to one-on-one conversations with a family about a person with dementia, communication often breaks down. Family members want information about the disease, how to manage symptoms, and what to expect as time goes on. They want to know where to turn as urgent questions arise, frequently outside office hours.

They are often left dissatisfied with the responses. Some health care and social service providers shrug off these questions with vague answers; others give statistics without explaining how the numbers might relate to a particular person. It's important to establish a trusting relationship in which families feel that they can ask any kind of question and have their immediate and future concerns addressed honestly and respectfully.²²

The New Jersey Family Health Survey²³ supports this notion. It found that 71% of family caregivers needed help finding services, 60% needed help learning about their family members' disease(s), and 46% needed help communicating with professionals.



24

²² Note to the Commission.

²³ "Facts and Findings, May 2015, Supporting Family Caregivers in New Jersey: Expressed Needs for Help Providing Home and Community-Based Care" p.1. Jennifer Rodriguez, Kristen Lloyd. Rutgers Center for State Health Policy. May 2015.

A common issue in dementia is known as “wandering”. A person with dementia may leave a home, a car, the side of a caregiver while in a store, and “wander” away. Often this happens when the person sees or hears something that he/she feels should be responded to or has sparked a memory. For example, the person may hear children playing outside and wander outside to join in or gather the children together. Wandering may result in a person walking into traffic, or even boarding a bus. A family caregiver may turn to take something off of a store shelf, and the person with dementia keeps walking straight.

“Elopement” is often the term used when there is active or forceful purpose to the wandering. A person may believe that “something” is wrong and they have to “escape” the house even through an open window. In the winter, it is common for people with dementia to feel they are “prisoners” because family members or home care aides are preventing them from leaving the house in freezing weather, leading them to become distraught and possibly physically forceful or even assaultive. One commenter expressed this viewpoint:

She needs guidance 24/7 but not necessarily care.²⁵

There is much that can be done to prevent wandering and elopement. There are also a growing number of options for post-event management. Unfortunately, these techniques and options are often resource-intensive. The largest resource required: people – people with undivided attention, on-demand replacement/supplementation and effective training.

Wandering and elopement are often the result of discomfort or a lack of direction (or redirection). People with dementia lose the ability to identify, understand, or articulate physical discomfort, such as arthritis pain or an upset stomach. They often express these feelings through a change in behavior, such as trying to leave an area or becoming aggressive. Pain management (as simple as acetaminophen or ibuprofen) can be tried to rule out this as a cause. Effective medical care can identify larger health problems, such as reflux or GERD, which can be treated or managed to reduce the discomfort. Reduce the pain, and the wandering or elopement is likely to be reduced as well.

People with dementia depend on others to provide direction. Due to the cognitive damage done to the brain by the Alzheimer's disease or other cause, people with dementia become confused by the world and require direction to stay engaged or to have a feeling of safety. Without direction by others, people with dementia can go seeking direction – something or someone to make the world make sense – and wander. Or the person may be distracted by a sound or a sight and wander to see it, or become distressed by it due to lack of understanding. This requires in-the-moment redirection. Unfortunately, such direction and redirection requires almost 24/7 attention by at least one person. That person is usually a family caregiver.

²⁴ “Facts and Findings, May 2015, Supporting Family Caregivers in New Jersey: Expressed Needs for Help Providing Home and Community-Based Care” p.2. Jennifer Rodriguez, Kristen Lloyd. Rutgers Center for State Health Policy. May 2015.

²⁵ Letter to the Commission.

After wandering or elopement occurs, the person must be found and brought to safety. The person may also need medical evaluation and care. Examples of resources for finding wanderers are:

- **MedicAlert® + Alzheimer's Association Safe Return®**: This program through the Alzheimer's Association involves a registry of people with dementia, including a photograph and emergency contacts, "Medic-Alert" bracelets and other on-person identification, and a toll-free number. If the person goes missing, the Association notifies the local hospitals and police. For every hour the person is gone, the alert goes to a larger area. Cost is minimal and there are subsidies.
- **Location systems**: There are an increasing number of location systems for finding a person with dementia. They range from on-demand monitoring to continual monitoring with alerts to a set group of people if the person leaves a predetermined area. GPS systems can be through a cellular telephone or a more covert device, such as a transmitter hidden in the sole of a special sneaker. In New Jersey, many county sheriff departments have a radio-signal bracelet system (Project Lifesaver) available at low- or no-cost.

Any of these tools require, at the end, the response and intervention of a person who needs to be available immediately and in close proximity.

Caregiver health: Dementia caregivers' health status deteriorates significantly over time, according to the analysis of the REACH 1 (Resources for Enhancing Alzheimer's Caregiver Health) study by the National Institutes of Health, published in 2012. Over the 18 months of the study, caregivers experienced a 25% increase in health care utilization, from doctor visits to hospitalization. Emergency room visits and hospitalizations alone doubled during this period.²⁶

Impact on children: In 2005 (the year of the only national study of children who are caregivers), it was found that at least 234,000 children ages 8-18 were caregivers for family members with Alzheimer's²⁷. Child caregiving is related to anxious or depressed behavior to feelings that no one loves them, difficulty concentrating in school, missing school or after-school activities, and absence from school.²⁸ Twenty-two percent of high school dropouts identified caring for a family member as a reason for leaving school. On the positive side, child caregivers are less likely to feel that too much is expected of them and are more likely to feel appreciated for what they do than non-caregiving children.

While several organizations have special programs and materials to support young caregivers (Alzheimer's Foundation of America's *AFA Teens*, Alzheimer's Association's videos and publications, Association for Frontotemporal Deterioration's materials and *AFTD Kids and Teens* website), there is

²⁶ Caregiving Costs: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient, p.5. National Alliance for Caregiving, Richard Schultz, Thomas Cook. National Alliance for Caregiving, Janssen, Alzheimer's Immunotherapy Program, and Pfizer. November 2011.

²⁷ "Young Caregivers in the U.S.: Findings from a National Survey" p. 5. Linda Naiditch, Carol Levine, Gail Hunt. National Alliance for Caregiving and United Hospital Fund. September 2005.

²⁸ "The Silent Epidemic: Perspectives of High School Dropouts" p. iii. John M. Bridgeland, John J. Dilulio, Jr., Karen Burke Morison. Civic Enterprises, Peter D. Hart Research Associates. March 2006.

only one organization in the United States dedicated to young caregivers: the American Association for Caregiving Youth (AACY). Based in Florida, AACY has an ongoing pilot project in South Palm Beach County schools to identify and support young caregivers. While these caregiving youth may be providing care for adults with any illness or disability, this project may be a model for New Jersey to explore.

Community Impact

The prevalence of Alzheimer's disease significantly impacts communities nationwide and in New Jersey, and has important implications going forward with the growing numbers of cases predicted. Because of the overall population increases for individuals age 65 and older, the country is expected to see an increase of at least 14% in the number of people with Alzheimer's disease, a growth that will affect every state and region across the country.²⁹

New Jersey's population was 8,899,339 in 2013 with 1,789,920 (20%) of those being age 60 and over.³⁰ Six counties accounted for just over half of New Jersey's population age 60 and older in 2013: Bergen (192,733), Ocean (159,976), Middlesex (145,821), Essex (131,717), Monmouth (128,407) and Morris (99,290).³¹ There is a significant gender gap among New Jersey's senior population. Women account for 56.3% of the population aged 60 years and older³² and 67.9% of the population 85 and older.³³

All communities are impacted by, and impact, people and families dealing with dementia in many other ways according to the professional literature:

- Growing challenge for State, county, and local social services to meet the safety and care needs of people with dementia and their family caregivers;
- Increased usage of police, emergency/ambulance, and fire services;
- Increased need for dementia-specific medical care in the community and hospitals;
- Reduced neighborhood participation and integration, with two or more people (person plus a caregiver) unable to attend church or social event, or needing special accommodation;
- Growing need for home care aide staff;
- People with dementia and their spouses and families are more at risk for abuse, neglect, and exploitation;
- Due to the cost of care and reduced working availability, caregiving families often have lowered ability to pay property taxes and make property improvements;
- Increased need for easily navigable public transit;
- Increased call for medical and other senior transportation;

²⁹ 2015 Alzheimer's Disease Facts and Figures, p. 18. Alzheimer's Association. 2015.

³⁰ US Census Bureau, 2013 American Community Survey 1-Year Estimates, Table S0102

³¹ Ibid

³² Ibid

³³ US Census Bureau, 2013 American Community Survey 1-Year Estimates, Table B01001

- Need for awareness by postal workers, public utilities, transit workers, bank tellers, and supermarket staff of people with dementia and how to manage mild confusion or behavioral problems in public areas; and
- Not-in-my-backyard (“NIMBY”) issues between neighbors of people with dementia, in developing community resource locations, and in building dementia-friendly housing.

Fortunately, there is much that can be done to support our communities – and is already being done in New Jersey. The recent report *Cognitive Aging: An Action Guide for Communities*³⁴ by the Institute of Medicines (IOM) of the National Academies outlines roles for community groups to help support the cognitive health of their constituents. The guide defines community groups as organizations, including senior centers, faith-based organizations, public health departments, nonprofits and private-sector groups. The IOM guide outlines actions for communities in the areas of promoting cognitive health, financial decision making and older adult driving.

The IOM guide cites specific actions for communities to take in terms of promoting cognitive health, from supporting increased physical activity, reducing cardiovascular disease risk factors, and managing medications effectively. Many such programs exist in New Jersey at the local, county and State levels in terms of aging services and health and wellness programs, through non-profit organizations and businesses. The state's over 70 hospitals are also actively involved in health promotion.

Workforce Impact

There are three primary areas to consider regarding the impact of Alzheimer's disease and other dementias on New Jersey's workforce: the impact on family members, the impact on employers, and the impact on care-related jobs and industry. As a resident said in a letter written to the Commission:

I have a full time job...Doctor appointments, medication management and financial oversight take up a good deal of my free time during the evening hours. I have used approximately two weeks of my vacation/paid time off (PTO) in 2014 to care for our father.³⁵

The amount of time diverted from employed work into unpaid caregiving of a relative, spouse, or friend with dementia is significant. In 2014, almost 22 hours per week were spent by family caregivers in caring for New Jersey residents.

³⁴ Cognitive Aging: An Action Guide for Communities. Institute of Medicine of the National Academies. 2015. Available at https://iom.nationalacademies.org/~media/Files/Report%20Files/2015/Cognitive_aging/action%20guide%20for%20communities.pdf.

³⁵ Letter to the Commission.

...when she came home I had to take family leave at my job. We could not afford private care at \$22.00/hour. My job let me go after three months and I was denied unemployment. They said caring for a family does not qualify.³⁷

Dementia care can also be a significant driver of our state's economy. Between nursing home care, home care, adult day care, pharmaceuticals, social services, hospital care, research, transportation, medical education, and data infrastructure, the care of people with Alzheimer's disease and other dementias directly employs thousands, and indirectly or partially employs thousands more. Our state's aging population creates high demand for the fields of homemaker, home health aide, and companion services. As a reflection of this, New Jersey certifies over 50,000 home health aides, licenses approximately 150,000 nurses, and has registry for 1,100 home care services firms and over 800 temporary ("temp") agencies that send out aides to a wide variety of health care settings.

³⁹ Best Practices in Workplace Eldercare. Donna L. Wagner, Andrea Lindemer, Kelly Niles Yokum, Mary DeFreest. National Alliance for Caregiving, ReACT. March 2012.

Dementia-specific education is required by our workforce. That need also creates improvements in our state's medical and nursing educational infrastructure, as well as new jobs. In 2015, Rowan University School of Osteopathic Medicine in collaboration with the Our Lady of Lourdes Health System, Camden Coalition of Health Care Providers, Area Health Education Centers, Bayada Home Care, Rutgers School of Nursing, and Trinitas Health System, secured one of 44 awards from the US Department of Health and Human Services, Health Resources and Services Administration (US DHHS-HRSA). The award created the New Jersey Geriatric Workforce Enhancement Program (NJGWEP).⁴⁰ This new program is designed to improve the quality of healthcare for older New Jerseyans. The goals include improving medical education by integrating geriatrics into primary care, with emphasis on assessing and addressing the unique care needs of the elderly as well as assisting their families. In addition, the NJGWEP will be integrating community-based programs into the program to increase the knowledge and skills of patients, families and professional caregivers.

Even volunteer efforts create employment and require infrastructure, because those volunteers must be organized, trained, and supervised – again, creating and maintaining jobs for New Jersey residents. For example, Ocean County's Area Agency on Aging (AAA) has been leveraging Older American Act Title III E (National Family Caregiver Support Program) funding to provide an Alzheimer's Respite Care Program since 2002. The service provider is the interfaith nonprofit Caregiver Volunteers of Central Jersey. Through this program, volunteers offer long-term, weekly support to family caregivers in their homes. Support can include anything from driving and errands to companionship to internet searches for resources. This program also builds paid jobs for New Jersey residents: the success of the volunteers depends on their training and ongoing supervision. A full-time coordinator is dedicated to this program. All volunteers go through the organization's routine volunteer training, plus:

- Additional training on:
 - Alzheimer's disease,
 - Other dementias,
 - Communication techniques, and
 - Behavioral management;
- Monthly continuing education and support;
- A full criminal background check;
- A driving history check;
- Supervised "matching" with program participants; and
- Periodic on-site observation.

All of these activities build the state's employment base, even though the direct services are provided by volunteers.

⁴⁰ The NJGWEP replaces the long standing New Jersey Geriatric Education Center (NJGEC) program, also awarded through US DHHS-HRSA. For additional information, see <http://www.hrsa.gov/about/news/pressreleases/150713geriatricworkforce.html>.

Financial Impact

The financial effects of Alzheimer's are challenging because it impacts:

- The individual with dementia and his/her ability to pay for care, as well as for regular life expenses;
- The individual's spouse, and his/her ability to continue to work and save, to maintain their home, and to afford care for him/herself;
- Other family members, who often assist financially as well as give up time from work (or work itself) to provide care; and
- The community and state at large, which has more of its citizens diverting their money from savings toward care expenses, needing assistance programs, selling homes, and requiring larger numbers of low-wage direct care employees.

The NJ4A, which represents New Jersey's 21 County Area Agencies on Aging (AAA), provided a letter to the Commission in which the following perspective was expressed on behalf of its membership:

The cost of care for those living with dementia is insurmountable...sometimes exceeding the life savings of caregivers, be they spouses, partners or adult children.⁴¹

People living with Alzheimer's disease or other dementias often cannot maintain employment due to the effects of the disease. The diagnosis can be financially devastating not only for a person 65 years old and over with a low income and little/no other retirement income, but also for younger, working age adults with early-onset Alzheimer's. One commenter wrote the following in a letter to the Commission:

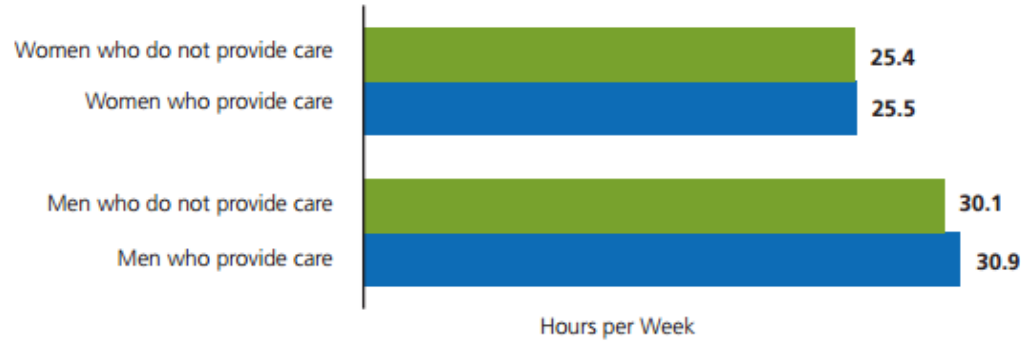
My wife was diagnosed at 58-years-old. I lost her income which was quite substantial. It is difficult to work to earn the money to pay the regular bills plus the extra expenses attributed to the disease, and still be there to care for her.⁴²

Early-onset Alzheimer's disease, or other young-onset dementias, frequently manifests after the person has the significant financial obligations common to American adulthood: education loans, mortgages, car loans and consumer debt, and expenses related to children. Not only is income lost, but savings for the spouse's future is sharply curtailed.

From the perspective of caregiving, there is little difference between working and non-employed caregivers. For example, the hours spent caregiving are virtually identical.

⁴¹ Letter to the Commission from NJ4A (New Jersey Association of Area Agencies on Aging, encompassing all 21 counties).

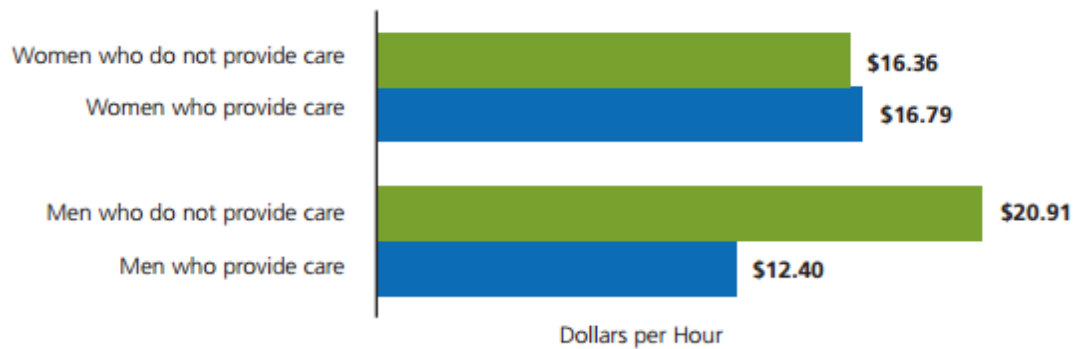
⁴² Letter to the Commission.

Figure 5: Average Hours Worked per Week, by Caregiving Status and Gender

Base: Working respondents.

43

The biggest workforce-type impact on working caregivers is in lost income and benefits. While there is only a modest difference in salary between caregiving and non-caregiving working women, there is a substantial difference for men – an \$8.51 per hour wage difference.

Figure 6: Median Hourly Wage, by Caregiving Status and Gender

44

For caregivers age 50 and over who leave the workforce to provide care for a family member, women lose an average of \$142,693 in wages, \$131,351 in Social Security, and \$50,000 in pensions. For male caregivers, these numbers change to \$89,107 in wages lost, \$144,609 in Social Security, and \$50,000 in pensions.⁴⁵

⁴³ "The MetLifeStudy of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents" p.11. National Alliance for Caregiving, Center for Long Term Care Research & Policy at New York Medical College, MetLife Mature Market Institute. June 2011.

⁴⁴ "The MetLifeStudy of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents" p.11. National Alliance for Caregiving, Center for Long Term Care Research & Policy at New York Medical College, MetLife Mature Market Institute. June 2011.

⁴⁵ "The MetLifeStudy of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents" p.2. National Alliance for Caregiving, Center for Long Term Care Research & Policy at New York Medical College, MetLife Mature Market Institute. June 2011.

If caregiving does not require or force a caregiver to become unemployed, the loss of income from lower work hours is significant. Reduced work hours may be from time away from work in excess of sick/vacation time, or from uncompensated family leave, or from an inability to work more hours due to caregiving duties.

Table 2: Impact of Parental Caregiving on Lost Wages and Social Security: Women

	Reduced Hours Working	Labor Force Exit
Lost Wages	\$120,616	\$142,693
Lost Social Security Benefits	\$64,433	\$131,351
Total Impact	\$185,049	\$274,044

Table 3: Impact of Parental Caregiving on Lost Wages and Social Security: Men

	Reduced Hours Working	Labor Force Exit
Lost Wages	\$126,934	\$89,107
Lost Social Security Benefits	\$37,923	\$144,609
Total Impact	\$164,857	\$233,716

46

Additionally, families often provide financial assistance to the person/couple. This graph illustrates the percentage of adult children who provide assistance to their parents:

Figure 4: Workers Versus Non-Workers Who Provide Financial Assistance, by Gender



Note: Financial assistance indicates that at least \$500 of support was provided to a parent within the past two years.

47

⁴⁶ "The MetLifeStudy of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents" p.14. National Alliance for Caregiving, Center for Long Term Care Research & Policy at New York Medical College, MetLife Mature Market Institute. June 2011.

Working or not, adult children often have to subsidize their parents' livelihoods. This responsibility reduces the funds they have available to save, to invest, and to provide for themselves and their children.

The financial cost of caregiving is of mixed benefit to New Jersey. While caregiving does have a negative impact on the finances of individuals and families dealing with dementia, care needs and caregiving fuel an entire industry and create jobs.

For example, in 2014 there were 33,540 home health aides employed in this state. There were 51,710 nursing assistants.⁴⁸ People in these jobs work in nursing homes, assisted living facilities, hospitals, home care agencies, and more. These positions can ease caregivers' responsibilities and allow them to manage their caregiving duties with work. Without this assistance, many caregivers experience great difficulty.

Impact on the State's Medical Infrastructure

The State of New Jersey has an extensive and well-developed health care infrastructure yet there are opportunities to build upon this basis to improve care and supports for individuals, families, communities, and health care providers who are affected by Alzheimer's and other types of dementia. At this time, there are many innovative healthcare models throughout the state involving care for people with dementia.

Hospitals: With regard to the amounts and varieties of care that our acute care system (hospitals and emergency departments) contend with to help the state's 170,000 people with dementia, this report provides a snapshot of the current infrastructure. There are 110 total hospitals in New Jersey, including specialty hospitals and about 70 acute care facilities. An increasing number of hospitals in all areas of the state are accommodating an aging population with specialized care through the creation of Acute Care of the Elderly (ACE) units to geriatric emergency departments and units, and the Nurses Improving Care for Healthsystem Elders (NICHE) initiative. Sometimes, improvements do not require major projects in order to have large impact. One caregiver suggested to the Commission that:

...Emergency Department procedures should be put in place to identify dementia patients. It would be as simple as a colored wrist band...It would help staff and families navigate the inter-department communications.⁴⁹

⁴⁷ "The MetLifeStudy of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents" p.10. National Alliance for Caregiving, Center for Long Term Care Research & Policy at New York Medical College, MetLife Mature Market Institute. June 2011.

⁴⁸ May 2014 State Occupational Employment and Wage Estimates: New Jersey. U.S. Department of Labor Bureau of Labor Statistics. Accessed at http://www.bls.gov/oes/current/oes_nj.htm#31-0000 on September 1, 2015.

⁴⁹ Letter to the Commission.

Alzheimer's and related dementias present particular challenges to hospitals. Recent Medicare data shows that about 25% of all hospital patients aged 65 and older have dementia. Compared with others in their peer group, older people with dementia have:

- Three times as many hospitalizations;
- Four times as many hospital days;
- Almost three times as many ER visits; and
- Hospital stays that are likely to be longer than usual for their primary diagnosis and to result in adverse outcomes such as a new delirium, pressure ulcers, incontinence, functional decline, physical restraints, psychotropic medications, untreated pain and new feeding tubes⁵⁰.

In addition, the family caregivers of people with dementia experience increased health care needs, as discussed in the "Impact on the Family" section of this report. With higher use of our state's health care system come higher costs: \$4,766 more per year, compared with non-caregivers⁵¹.

Yet hospitals are only one piece of the medical infrastructure that touches individuals with Alzheimer's disease. In examining the state's current healthcare system, acute rehabilitation centers, subacute rehabilitation units, skilled nursing facilities, personal care homes, adult day centers, home care agencies, medical clinics and private practices, geriatric assessment centers, and assisted living facilities also need to be considered.

There are a number of innovative pilots and successful best practices taking place in many of these settings, as well as opportunities for quality improvement and increased capacity to meet the needs of our state's growing dementia population. It's important to note that it's not just about the number of people served but the quality of the services provided.

Nursing homes: Currently New Jersey has about 370 nursing homes or approximately 40,000 beds (including for people with ventilator-assisted breathing), with about 68% of these beds used by individuals receiving Medicaid. Traditionally nursing homes were thought of as both the primary place for long-term dementia care and as a last resort. Fortunately, nursing homes have evolved significantly over the past 28 years, starting with the Omnibus Reconciliation Act of 1987 (OBRA 87).⁵² Changes to everything from care requirements to monitoring of medication options, combined with longer lives,

⁵⁰ "Reducing the Stress of Hospitalization for Patients with Dementia and Their Family Caregivers". Next Step in Care. Accessed at http://www.nextstepincare.org/uploads/File/Guides/Provider/Provider_Dementia.pdf on August 25, 2015.

⁵¹ Caregiving Costs: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient, p.1. National Alliance for Caregiving, Richard Schultz, Thomas Cook. National Alliance for Caregiving, Janssen, Alzheimer's Immunotherapy Program, Pfizer. November 2011.

⁵² "Nursing Home Reform: Then and Now" (video). The Henry J. Kaiser Family Foundation. 2007. Accessible at <http://kff.org/medicare/video/nursing-home-reform-then-and-now/>.

have made nursing homes become a place where people who need significant care go to live their final years.

Nursing homes are required to conduct continuous quality improvement activities. They are also aided by local resources, including the New Jersey Hospital Association, the Healthcare Association of New Jersey and LeadingAge New Jersey, for quality improvement support and best practices. Tools such as *QAPI at a Glance: A Step by Step Guide to Implementing Quality Assurance and Performance Improvement (QAPI) in Your Nursing Home*, created by the Centers for Medicare and Medicaid Services (CMS), University of Minnesota, and StratisHealth, are readily available.

National models of redesigned care are beginning to emerge in New Jersey. The Francis E. Parker Memorial Home in Piscataway and several other nursing homes are utilizing the Eden Alternative®, which changes how daily care is delivered, putting determination into the hands of residents and the direct care staff (instead of the traditional top-down administrator/medicine/nursing control structure). Green Hill in West Orange is the first facility to create new buildings, using the Green House Project® method. The Eden Alternative calls on nursing homes to restructure existing facilities' daily routine to suit the residents, not the staff, and to integrate plants, homelike features and the larger community (especially children) into the nursing home. The Green House Project takes the Eden Alternative concept further, requiring smaller facilities that are designed and run more like family homes. Both are significant departures from the traditional medical model of care.

Since 2011, the NJ Department of Health (DOH) has been involved in the Partnership to Improve Dementia Care, a national initiative with the Centers for Medicare & Medicaid Services (CMS) to ensure appropriate care and use of antipsychotic medications for nursing home residents. The initiative's goal is to reduce the inappropriate use of antipsychotic medications by 15% nationally in residents with dementia. The initiative includes research, revised surveyor guidance, training for providers and surveyors and public reporting — steps that the DOH has taken in collaboration with New Jersey's nursing home industry. New Jersey is ranked fourth best among the nation's states in terms of its usage of such medications and has achieved significant reduction in its rate of antipsychotic usage: down by about 18% between the end of 2011 and the end of 2013. Furthermore, the licensing regulations for long-term care facilities under the auspices of DOH support the reduction of over-prescribing of antipsychotic medications, turning this practice into a statewide effort.

Since the launch of the National Partnership to Improve Dementia Care (Partnership), significant reductions in the prevalence of antipsychotic use in long-stay nursing home residents have been documented. The National Partnership continues to work with state coalitions and nursing homes to further reduce that rate. Recently, CMS established new national goals for reducing the use of antipsychotic medications in long-stay nursing home residents by 25% by the end of 2015, and 30% by the end of 2016. These goals build on the progress made to date and express the Partnership's commitment to continue this important effort.

While the initial focus was on reducing the use of antipsychotic medications, the Partnership's larger mission is to enhance the use of non-pharmacologic approaches and person-centered dementia care practices. CMS plans to monitor the reduction of antipsychotics, as well as the possible consequences, review the cases of residents whose antipsychotics are withdrawn to make sure they don't suffer an unnecessary decline and add the antipsychotic measure to the calculations that CMS makes for each nursing home's rating on the agency's Five Star Quality Rating System.⁵³ New Jersey has been able to capitalize upon CMS's efforts by tapping into the Civil Monetary Penalty Fund and create residencies for registered nurses. These residencies expose the nurses to music therapy as a dementia care modality in long-term care – part of the overall strategy to build skills in non-pharmacologic dementia management.

Geriatric mental health: New Jersey has been on the forefront of innovative care for the elderly with behavioral issues. In 1994 the state, in partnership with the UMDNJ School of Osteopathic Medicine, Center for Aging (now the Rowan University School of Osteopathic Medicine, New Jersey Institute for Successful Aging) and the Silver Care Center (now Alaris, Cherry Hill), opened the first 40 bed behavioral management unit to deal with Alzheimer's Disease. These are known as Specialty Care Nursing Facilities (SCNF).

Since then, three other such units have opened: Absecon Manor in Absecon; Christian Health Care Center in Wyckoff; and Preakness Center in Wayne. The goal of the four SCNFs has been to provide a temporary setting to resolve behavioral issues in adults with dementia. The units are staffed with a higher staff-to-patient ratio than traditional nursing homes. Activity programs especially geared for individuals with behavioral issues are part of the hallmark of these units. Admission is restricted to those who meet specific criteria and require an additional behavioral evaluation, separate from the standard PASRR (Preadmission Screening and Resident Review) process, to ensure the SCNF is the best setting to address the individual's behavioral health issues. In addition, each of the four units has a functioning inter-professional geriatric team lead by either a geriatric psychiatrist or a geriatrician. The overall goal is to prevent psychiatric hospitalization. In the case of the Alaris unit, in the past 22 years, only 6 patients have required psychiatric hospitalization.

The nationally recognized Statewide Clinical Outreach Program for the Elderly (S-COPE) through Trinitas Regional Medical Center in partnership with Rowan University School of Osteopathic Medicine's New Jersey Institute for Successful Aging provides crisis intervention and stabilization, consultation, and training for the management of mental health and behavioral issues in older adults (age 55 and over) residing in nursing homes and other residential care facilities. It functions as a multidisciplinary team consisting of a geriatric psychiatrist, geriatric advanced nurse practitioners and Master's level clinicians whose members are also available 24/7 in crisis settings to prevent unnecessary inpatient psychiatric hospitalization. S-COPE is located at the Trinitas campus in Elizabeth (Union County), and serves a statewide population.

⁵³ For more information, see <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html>.

Health care in the community: Home care agencies (Medicare-certified agencies and licensed agencies), hospice agencies, rehabilitation groups, and more provide care at the person's home. Physicians, nurse practitioners, physician assistants, nurses, multiple types of medical technicians, physical and occupational therapists, therapy aides, certified nurse aides, licensed and clinical social workers, psychologists, and home health aides are just a few of the professionals and paraprofessionals who provide, supervise, and are held responsible for care of people with dementia.

A national model that New Jersey has embraced with success is Program for All-Inclusive Care of the Elderly (PACE). PACE is a joint venture of Medicare and Medicaid for community-dwelling people age 55 and over who require a nursing home level of care. The concept is to provide highly coordinated Medicare and Medicaid services to maintain the participant at home. PACE can also be paid for privately. In New Jersey, PACE programs are referred to as LIFE (Living Independently For Elders). There are currently five PACE programs in New Jersey:

1. LIFE St. Francis (St. Francis Medical Center), for residents of Mercer and parts of Burlington Counties;
2. LIFE at Lourdes (Our Lady of Lourdes Medical Center), for Camden County;
3. Lutheran Senior LIFE (Jersey City Medical Center), for Hudson County;
4. Inspira LIFE (Inspira Health Network), for parts of Cumberland, Gloucester and Salem Counties; and
5. Beacon of LIFE (Beacon Health and Social Services), for much of Monmouth County.

Physicians: A significant issue for New Jersey is ensuring quality of dementia care, notwithstanding the care setting. New Jersey physicians are the seventh oldest in the nation, with 28% of actively practicing physicians at age 60 or above.⁵⁴ New Jersey has three Geriatric Medicine/Family Medicine Fellowship programs: Rutgers-New Jersey Medical School, Rutgers-Robert Wood Johnson Medical School, and Rowan University School of Osteopathic Medicine. Currently, New Jersey has one Geriatric Psychiatry Fellowship program, which is based at Rowan University School of Osteopathic Medicine. Dementia-type disorders, such as Alzheimer's disease or frontotemporal dementia, require initial screening, testing and diagnosis, ongoing management, end-of-life care, and an adequately trained physician workforce. One letter received by the Commission noted the following situation:

My mother, for years, had been displaying signs of disorganization, inability to follow complex stories or directions to a new gadget. She had piles and piles of note pads with daily notes scribbled on them of the most mundane things...Then two years ago when she started dropping weight, crying daily, telling me she was depressed and lonely...Her MD laughed it off as "senior

⁵⁴ "2011 State Physician Workforce Data Book" p.20. Center for Workforce Studies and Association of American Medical Colleges, with data from the December 31, 2010 American Medical Association Physician Masterfile.

moments" and told me she passed some five question test just fine and said losing 20 pounds was healthy!!!⁵⁵

Geriatric assessment centers developed in New Jersey in the mid- and late-1980s. These are a geriatrician-led multidisciplinary team approach to evaluation and care of older adults. This model is widely used in the Department of Veterans Affairs (VA) system nationally. Currently, there are geriatric assessment centers at approximately seven non-VA locations across the state, including the New Jersey Institute for Successful Aging at Rowan University, Robert Wood Johnson Medical School of Rutgers University, Center for Healthy Aging of Hunterdon Healthcare, and Morristown Medical Center of Atlantic Health System. Geriatric assessment centers may provide consultation assessments only, or may provide ongoing primary care for the older adult. The multidisciplinary nature of the assessments, which evaluate not only immediately reported and visible health but also the patient's history and health contributors (such as nutrition, access to supportive services, home situation, and mobility), often lead to better health outcomes than routine care by a community physician.

End-of-life: Part of our ongoing national discussion is end-of-life care. New Jersey physicians see this presented every day, at home, in hospitals, and in long-term care facilities. A retired medical doctor provided this comment to the Commission:

I am a recently retired Emergency Medicine physician...For years I would see the merry-go-round of severely demented nursing home bound patients wheeled into the Emergency Department on ambulance gurneys with fevers or other...changes in their baseline status to be admitted to the hospital and treated for their acute pulmonary, urinary tract or skin infections, subsequently be discharged and then be readmitted within weeks or months.⁵⁶

With the exception of palliative care physicians and advance practice nurses, medical professionals are rarely taught how to have conversations with patients and families about the end of their lives. As another commenter described:

Neurologists are reluctant to tell a person and his/her family that the early symptoms are Alzheimer's. Instead the label is mild cognitive impairment (MCI)⁵⁷. This may be technically correct, but when the mild stages advance to moderate dementia, caregivers are often caught off-guard, especially as the dementia accelerates at a rapid pace. The affected individual is now incapable of meaningfully contributing to decisions about immediate and end-of-life care.⁵⁸

A century ago, death was a daily occurrence; women died young in childbirth, men died young in workplace accidents and families had many children because only a few would survive to adulthood. Options for prolonging life through medicine and machines did not exist. Now, unfortunately, the older

⁵⁵ Letter to the Commission.

⁵⁶ Letter to the Commission.

⁵⁷ Mild Cognitive Impairment is an often stable neurocognitive condition with approximately 28% of patients progressing onto dementia. For more information, see <http://www.ncbi.nlm.nih.gov/pubmed/24353333>.

⁵⁸ Letter to the Commission.

a person gets, the more likely that person is to develop Alzheimer's or another dementia. Also now, we do have options for extending the life of that person with cognitive loss.

New Jersey has enacted POLST (Physician's Orders for Life Sustaining Treatment), which Governor Christie signed into law in December, 2011 (N.J.A.C. 26:2H-130). The New Jersey Hospital Association⁵⁹ and the NJ Department of Health⁶⁰ have created resources to assist health care providers in actualizing POLST in various settings. The POLST and its decisions for the end of life are certainly a step forward in assisting amidst the ongoing, often crisis-oriented health care decisions that family caregivers and their medical providers face. The POLST is designed to be followed in any care setting.

The strength of POLST (and any other advance planning tool) is the conversation between that physician or advanced practice nurse and the patient. If the conversation is not based on clear and open discussion of diagnoses, prognoses, options for treatment and the likely outcomes of that treatment, and options for daily care, then the POLST will not effectively guide medical care. For example, a frail elderly woman with multi-infarct dementia (related to lifelong hypertension) may make a different decision about CPR (cardio-pulmonary resuscitation) if her physician discusses the likely outcomes of CPR for a person in her condition. And people need to know the likely trajectory of their family member's Alzheimer's before deciding about a feeding tube: will it help him enjoy the remainder of life, or is it likely that the person will continue to lose weight and have bouts of pneumonia?

Many people do not want to discuss these issues. Some people expect doctors to tell them what to do, or to initiate the conversation. The medical system neither teaches nor supports physicians in how to talk with patients or families. It also does not teach physicians on how to be at peace with the patient who cannot be fixed. As the national caregiving expert Carol Levine stated in the "Impact on the Family" section of this report and the commenters quoted in this section have identified, communication is key.

New Jersey's POLST is unique. It supports effective communication through its design and includes the goals of care. "Goals of care" speak to the purpose of a procedure, treatment, and overall daily care. Common topics include balancing prolonging life with comfort, alertness and interactions with family, and unfinished life tasks. Once the overall goals of care are decided by the person and the doctor or advanced practice nurse, then every option for care – from food choices to medication to the care setting itself – is weighed with those goals in mind.

Medical research: New Jersey is home to 14 of the world's twenty largest pharmaceutical companies.⁶¹ The state is known as the "Medicine Chest of the World." More biopharmaceutical companies refer to New Jersey as home than any other state in the country, or any country in the world.

The biopharmaceutical and medical technology industry is a major factor in creating a thriving economy in New Jersey, as well as making the state a leader in research and development. According to the

⁵⁹ Available at <http://www.njha.com/quality-patient-safety/advanced-care-planning/polst/>.

⁶⁰ Available at <http://www.nj.gov/health/advanceddirective/polst.shtml>.

⁶¹ <http://www.nj.gov/njbusiness/industry/pharmaceutical/>, accessed on 10/4/15.

HealthCare Institute of New Jersey's (HINJ) *2013 Economic Impact Report*, New Jersey-based facilities alone invested \$8.67 billion in R&D activity in 2012. New Jersey is the site of 2,200 active or open clinical trials.⁶² Several of those companies are actively involved in developing treatments to prevent and manage Alzheimer's.

With regard to innovation, New Jersey's life sciences companies have invested vigorously in research and development even in the most challenging of economic times. They have done so because R&D — the painstakingly complex and costly search for new medicines, therapies and technologies — is the engine that drives this industry and secures its future.

Supporting and conducting research in New Jersey are the state's four medical schools and 13 teaching hospitals. New Jersey has the nation's highest concentration of scientific professionals with 126,000 life sciences/biopharma workers statewide. Each year more than 22,000 students graduate with degrees in the life sciences from New Jersey's state universities.

Training of New Jersey's healthcare workforce: New Jersey's healthcare Industry is projected to grow and add jobs in the state. From 1990 through 2014, the health care sector has added 191,600 new jobs, while other private sector employment has seen a net increase of only 91,700. From 2012 through 2022, it is projected that nearly 89,200 jobs will be added and the outlook for job growth is bright.⁶³ Health care employers paid more than \$23.3 billion in total wages in 2013, or about 12.2% of all wages paid.⁶⁴ Health care employment is comprised of three industry groups: ambulatory health care services (47%), hospitals (32%), and nursing and residential care facilities (21%).⁶⁵

The NJ Department of Labor and Workforce Development's (NJLWD) spring 2015 presentation labeled "New Jersey's Health Care Cluster" points to these highlights in the overview:

- There are roughly 21,460 establishments employing nearly 442,900 people of all ages, genders, race and educational backgrounds in New Jersey in 2013. While the majority of these establishments are smaller offices of health care professionals, nearly one-third of all employment is found in hospitals.
- The majority of occupations in health care do not even require a two-year degree. Average salary tends to correlate with education; the more you learn, the more you earn.
- The profile of the average health care industry worker is overwhelmingly female, aged 35-54, and has some postsecondary education. It is also a more diverse workforce than average.

In 2011, NJLWD launched six talent networks, identifying healthcare as one of its key economic sectors. Since then, the Healthcare Talent Network, funded by NJLWD and based at Rutgers' School of

⁶² <http://www.nj.gov/njbusiness/documents/industry/Pharma.pdf>

⁶³ <http://lwd.state.nj.us/labor/lpa/pub/empecon/healthcare.pdf>

⁶⁴ <http://lwd.state.nj.us/labor/lpa/pub/empecon/healthcare.pdf>

⁶⁵ <http://lwd.dol.state.nj.us/labor/lpa/pub/lmv/cluster%20handout.pdf>

Management and Labor Relations, has been integrating information from employers about their workforce needs with data from market analysis in order to strengthen the capacity of the workforce to have the skills to match the industry's jobs, now and in the next 10 years. Strategies to promote this alignment is coming from partnerships with the state's workforce training initiatives and institutions, its community colleges, universities and other providers of technical and apprenticeship opportunities.

The Healthcare Talent Network is bringing together key stakeholders invested in New Jersey's health care workforce. It aims to ensure that the skills in the field keep pace with the changing demands of this key sector of New Jersey's economy. The network also serves as a comprehensive resource, providing specialized services for employers, jobseekers, educators and labor professionals.

Other stakeholder groups that are currently addressing health care workforce issues in New Jersey include the:

- NJ Health Care Workforce Council. The Council, which resides in the NJ State Employment and Training Commission, was created to develop and strengthen the state's health care workforce and to support a sustainable and quality health care system.
- NJ Nursing Initiative. The New Jersey Nursing Initiative (NJNI) is a multi-year, multi-million-dollar project of the Robert Wood Johnson Foundation (RWJF) and the New Jersey Chamber of Commerce Foundation. NJNI's goal is to increase the number of nurse faculty in the state, so there will be enough nurses to meet the health care needs of New Jersey residents.
- John J. Heldrich Center for Workforce Development. The university-based research and policy center is dedicated to raising the effectiveness of the workplace by strengthening workforce education, placement and training programs and policies.
- NJGWEP. For details, please see the *Workforce Impact* section of this report.

From licensed health professionals to direct care workers, all health care workers will need enhanced training and education in geriatrics and gerontology to meet the unique needs of older New Jerseyans living with dementia. NJLWD notes that New Jersey's aging population has increased the demand for health care services, especially in the areas of nursing and residential care. It is the state's aging population that is among the major drivers that will increase the demand for health care. As the baby boomer generation continues to age, the demands they place on the health care system will drive employment higher.

Yet despite these positive growth trends in New Jersey's health care sector, there are three basic components that determine quality of care for a person with Alzheimer's disease in any setting according to the Alzheimer's Association. These factors comprise sufficient staffing levels, appropriately compensated staff, and proper training, including dementia specific training — and should be addressed in efforts to prepare the state's workforce for the emerging Alzheimer's population.

Impact on the State's Community Resources

New Jersey has a very wide range of resources in the community available to people with dementia and their families. This section provides a broad overview by source, and then describes several specific areas.

The NJ Department of Human Services (DHS) collaborates and partners with federal, State and community-based organizations to maximize resources and provide an array of high-quality services statewide that promote independence, dignity, choice and assistance for aging adults, individuals and families with low income, and people with disabilities.

This section provides a broad overview by source and then highlights several specific focus areas:

1. Federal

- a. Medicare: Health insurance for Americans aged 65 and older who have worked and paid into the system. It also provides health insurance to younger people with disabilities.
- b. Family Medical Leave Act (FMLA): Allows caregivers of immediate family members to take unpaid but limited time off from work to provide care.
- c. Older Americans Act: Services provided through this Act form the backbone of New Jersey's community-based, nonmedical resources for older adults, including those with dementia and their caregivers. Older Americans Act funding is under the authority of the Administration for Community Living (ACL).
- d. Social Security: The national employee/employer-contributed pension system. Often the only or primary source of income for older adults and younger adults with significant disabilities such as early-onset dementia (through Social Security Disability).

2. State

- a. NJ FamilyCare: Through the State's NJ FamilyCare program, the Division of Medical Assistance and Health Services (DMAHS) provides New Jersey's eligible, uninsured residents with access to low or no cost health care. DMAHS works closely with the Divisions of Aging Services (DoAS), Mental Health and Addiction Services (DMHAS) and Developmental Disabilities (DDD) to advance comprehensive initiatives, including Managed Long Term Services and Supports (MLTSS), the Interim Managing Entity (IME) and home and community-based services (HCBS) for individuals with intellectual and developmental disabilities.
- b. Division of Aging Services: The Division on Aging Services (DoAS) administers the Older Americans Act funding under DHS, which is the State Unit on Aging. In addition, DoAS administers other programs such as the Congregate Housing Services Program, the Jersey

Assistance for Community Caregiving (JACC), the Statewide Respite Care Program, Alzheimer's Adult Day Services Program, and the Program of All-inclusive Care for the Elderly (PACE). DoAS also has responsibility for a host of benefit programs. They include the operation of two prescription drug assistance programs (Pharmaceutical Assistance to the Aged and Disabled and Senior Gold Prescription Discount Program) as well as the Lifeline Utility Assistance program and the Hearing Aid Assistance to the Aged and Disabled program.

Managed Long Term Services and Supports (MLTSS) began operating statewide on July 1, 2014. While MLTSS is housed within the Division of Medical Assistance and Health Services (DMAHS), DoAS retains an important operational role in the program, from options counseling to clinical eligibility determination and quality assurance.

- c. New Jersey Family Leave Act (NJFLA): An expansion on the federal FMLA described above, NJFLA allows employees to take unpaid time in small increments for caregiving. For families dealing with dementia, this can be crucial for accompanying the person to doctors' appointments, managing daily care issues and dealing with crises.
- d. Elder justice and protection: New Jersey's Adult Protective Services (APS) Act provides units in each county for the investigation of abuse, neglect, and exploitation of senior citizens and disabled adults residing in the community. APS is under the auspices of DoAS. The Office of the Public Guardian (OPG) provides guardianship services for those adults whom the courts have determined require guardianship and have no family or friend who can do so. County and State prosecutors pursue cases of substantiated abuse, neglect, and exploitation.
- e. Pharmaceutical and hearing aid assistance: The PAAD (Pharmaceutical Assistance to the Aged and Disabled), Senior Gold, and HAAAD (Hearing Aid Assistance to the Aged and Disabled) programs subsidize the costs of prescriptions and hearing aid devices.

3. County

- a. Area Agencies on Aging (AAAs): Often called "offices on aging," these are the front-line providers of services from the Older Americans Act, Casino Revenue Fund, and county funding. The county AAA (pronounced "triple A") is the primary advocate to the State and others for the older adults and younger, disabled adults they serve. Primary functions of the AAAs are: providing information to the community about services and topics of interest, assisting people to obtain those services, and managing the provision of many of those services. The information and assistance roles are part of the Aging and Disability Resource Connection (ADRC) network of the State Unit on Aging. Each of the State's 21 AAAs either directly provide or contract with local organizations to provide services that can include:
 - i. Home delivered and group (congregate) meals

- ii. Home repair
 - iii. Legal services
 - iv. Caregiving supports
 - v. Non-medical home care, homemaker, and housekeeping
 - vi. Personal emergency response systems (PERS)
 - vii. Evidence-based exercise and mobility classes
 - viii. Adult day care services
 - ix. Care management
 - x. Money management
 - xi. Non-medical transportation for appointments, shopping, and recreation
- b. Sheriff Department: Manage Project Lifesaver, a dementia tracking system described in detail in the “Impact on Public Safety” section of this report.
 - c. Boards of Social Services: May serve as the County Welfare Agency, which processes NJ FamilyCare, NJ SNAP (Supplemental Nutritional Assistance Program), and TANF (Temporary Assistance for Needy Families) applications. Often Boards of Social Services provide case management, rental assistance, and other services.
4. Local
- a. Local Health Departments: Provide low- or no-cost medical services, such as dental care for senior citizens, influenza vaccines, cholesterol screening, and more. They usually also provide nursing visits to homebound senior citizens.
 - b. First responders: Police, ambulance corps, and fire departments are frequently called upon to assist with everything from a wandering person to people who have fallen and need to be lifted up. This is discussed in more detail in the “Impact on First Responders” section of this report.
5. Private
- a. Community-based agencies
 - b. Faith-based communities and supports
 - c. Workplace employee assistance programs and other employer-sponsored supports

- d. Volunteer groups
- e. Philanthropic organizations
- f. Advocacy organizations

Two examples of community resources that could potentially be replicated statewide were highlighted in comments made to the Commission by the New Jersey Association of Area Agencies on Aging (NJ4A). These two AAAs have leveraged a variety of funding and talent sources to offer “concentrated and tailored caregiver education” for families:

- Mercer County offers the Skills2Care program through its caregiver education program and federal Title III-E funding. It offers a tailored program structured to support caregivers along their caregiving journey. By pairing an occupational therapist with a caregiver, both environmental cues and behavioral concerns are addressed in hopes to minimize challenging behaviors.
- Gloucester County shares that one agency it works with offers a specialty program that uses computerized custom software to create a daily schedule. The plan includes meaningful tasks and activities based on a client's personal interests and appropriate for the individual's current level of dementia. Caregivers are provided with advanced dementia training as well as individualized, ongoing instruction from a care manager. Follow-up visits occur to regularly assess the current level of dementia and modify activities for the person with dementia.⁶⁶

Focus Area: Managed Long Term Services and Supports

New Jersey has a 20-plus year commitment to creating a long-term services and supports system that emphasizes HCBS and relies less on institutionalization. With its move to Managed Long Term Services and Supports (MLTSS) through the federal government's approval of a five-year Medicaid Section 1115 research and demonstration waiver in October 2012 (the New Jersey Comprehensive Waiver), the state is even better positioned to serve more individuals with HCBS. As part of the demonstration, New Jersey launched MLTSS effective July 1, 2014 with the goal of providing holistic care to as many people as possible with HCBS.

MLTSS refers to the delivery of long-term services and supports through New Jersey Medicaid's NJ FamilyCare managed care program. MLTSS expands HCBS, promotes community inclusion and ensures quality and efficiency. MLTSS uses NJ FamilyCare managed care organizations (MCOs) to coordinate all services for their members: acute and primary health care services and their long-term services and supports. MLTSS provides comprehensive services and supports, whether at home, in an assisted living facility, in community residential services, or in a nursing home. It comprises personal care, respite, care management, home and vehicle modifications, home delivered meals, personal emergency response

⁶⁶ Letter to the Commission.

systems, mental health and addiction services, assisted living, community residential services, and nursing home care.

For the person whose income is too high for MLTSS qualification, but whose assets are depleted and cannot pay for the care necessary, New Jersey now has a Qualified Income Trust policy, also known as a Miller Trust. This program, which was effective December 1, 2014, allows an individual to become eligible for MLTSS by placing gross income into a separate bank account each month. The QIT involves a written trust agreement, setting up the special bank account and depositing income into the account. QITs also have special conditions that must be met and are subject to the approval of, and monitoring by, the appropriate Medicaid eligibility determining agency.

Focus Area: Down Syndrome

The Division of Developmental Disabilities (DDD) provides funding for a wide range of day, residential and family support services in the community for eligible New Jersey residents with developmental disabilities. These programs are designed to serve as added tools for use in creating dynamic, individualized care of all participants. DDD works to provide the most appropriate services to the individuals it serves through the expansion of community supports and services and helping individuals remain at home with their families for as long as possible.

The Community Care Waiver (CCW) is a Medicaid Waiver program for individuals with developmental disabilities that pays for the services and supports that individuals need in order to live in the community. Administered by DDD, the CCW is funded by the State and federal government. The CCW is a critical component of DDD's ability to provide services in the community to individuals with developmental disabilities.

The Supports Program, which was implemented in July, 2015 as part of the NJCW demonstration, provides a basic level of support services to participants who live with family members or who live in their own homes. The Supports program has expanded the services available to adults with intellectual and developmental disabilities by providing services to individuals who are Medicaid eligible and meet the functional criteria to receive services funded through DDD (excluding people currently served on the CCW). Individuals are able to select their own services, based on their assessed needs, from a menu that includes: support coordination, assistive technology, behavioral management, cognitive rehabilitation, community based supports among many other services. The Supports Program provides expanded opportunities for individuals with intellectual and developmental disabilities to live fully integrated in their communities.

Focus Area: Fraud, Abuse, and Neglect

In New Jersey, Adult Protective Services (APS) programs operate in each county to receive and investigate reports of suspected abuse, neglect and exploitation of vulnerable adults living in a community setting. In 2010, the APS statute (N.J.S.A. 52:27D-406 to 426) was amended to require health

care professionals, law enforcement officers, firefighters, paramedics or emergency medical technicians who have reasonable cause to believe that a vulnerable adult is the subject of abuse, neglect or exploitation to report that information to the county Adult Protection Services office.

Communities can also take action in the area of taking protections against financial fraud and abuse. About a million older Americans lose an estimated \$2.6 billion annually as a result⁶⁷. "Cognitive Aging: An Action Guide for Communities" by the Institute of Medicine identifies possible directions, ranging from offering consumer financial education programs and working with financial institutions.⁶⁸

Focus Area: Person-Centered Care

Person-centered care "promotes choice, purpose and meaning in daily life. Person-centered care means that [the person is] supported in achieving the level of physical, mental and psychosocial well-being that is individually practicable."⁶⁹ While the concept of patient-centered care puts the patient's needs first, person-centered care looks beyond the "patient" to the whole person.

Many of the comments made to the Commission at the Listening Sessions and in written remarks called for person-centered care. One commenter expressed the following:

Through his final years, though his communication skills and memory eroded, he was able to express himself through painting, a craft to which he had shown no prior acumen. Listening to music of all genres gave him a sense of ease, especially the melodies that would make him dance! For the sake of the spirits of these patients, please set aside funding for these forms of relaxation and self-expression.⁷⁰

While the person with Alzheimer's disease or other dementias may not be able to reach out independently and communicate, there are non-verbal ways for us to reach in, such as through art and music. Such person-centered care may not require additional staffing or funding, but is often dependent on training, readily available supplies and workplace environments that are supportive.

Age can also be a factor in person-centered care as another commenter noted:

⁶⁷ Broken Trust: Elders, Family, and Finances. MetLife Mature Market Institute, the National Committee for the Prevention of Elder Abuse, and the Center for Gerontology at Virginia Polytechnic Institute and State University. March 2009.

⁶⁸ Cognitive Aging: An Action Guide for Communities, p.3. Institute of Medicine of the National Academies. Accessed 8/12/15 at [http://www.iom.edu/~media/Files/Report Files/2015/Cognitive_aging/Online Resources for Older Adult Driving_V2.pdf](http://www.iom.edu/~media/Files/Report%20Files/2015/Cognitive_aging/Online%20Resources%20for%20Older%20Adult%20Driving_V2.pdf).

⁶⁹ Advancing Excellence in America's Nursing Homes Campaign, accessed 12/7/15 at <https://www.nhqualitycampaign.org/goalDetail.aspx?g=pcc>.

⁷⁰ Letter to the Commission.

There seem to be no programs or places for an under-65 functioning person to be able to go with other Early Alzheimer's patients... It's as if no one assumes that there are patients who are young.⁷¹

Even architecture plays a part in person-centered care, as described in the comment below:

... the lack of "family" bathrooms in public spaces is a real issue. Many of those with moderately-severe dementia are incapable of handling a toilet on their own. What is an opposite-sex caregiver to do when only "men's" and "women's" rooms are available? New Jersey needs more "family" bathrooms in public places so that those with dementia may be assisted by opposite-sex caregivers.⁷²

In an effort to care for New Jerseyans with dementia and their families, all aspects of an individual's life must be considered. The message that so many commenters voiced was that "care" is not the goal: a worthwhile life is. That life was described as supported by the workplace and the community, at home if at all possible. Commenters shared that there was little difference between people with dementia and people without, that the needs of people with dementia and their families were not extraordinary, and that a reasonable degree of consideration would improve life for all.

As an outgrowth of person-centered care, commenters also made a strong case for clear channels of communication with healthcare professionals about the disease progression now and in the future as well as a way to access help with fewer barriers along the way. Many felt that healthcare professionals leave the raising of "tough" issues to families, or that those professionals did not provide the depth and scope of information families required in order to make informed decisions and know how to obtain assistance. Healthcare professionals, especially physicians, were seen as a natural gateway for family and patient support.

Public Safety Impact

Public safety affects and is affected by Alzheimer's disease and other dementias. From the person who forgets the pot on the stove and starts a house fire to the caregiver who calls the police to control a violent, confused 75-year-old family member who thinks that 3:00 a.m. is time to go to school, our first responder resources and personnel are impacted by dementia. On the other hand, public safety impacts people with Alzheimer's and their families in how communities are structured, and how first responders respond to crises, or fail to respond.

Neighborhood design can positively or negatively affect the safety of people with dementia. Streets and sidewalks that are all the same color cause falls, since people with Alzheimer's or Lewy body dementia

⁷¹ Letter to the Commission.

⁷² Letter to the Commission.

have difficulty with spatial relationships such as knowing that the stair is higher than the sidewalk, or the road is lower than the curb. Driveways blocked in by snow “humps” after town plowing prevent services from coming into a home and people from going out to day programs, creating isolation and increasing the risk for negative dementia behaviors or even caregiver abuse or neglect.

Wandering and elopement: When a wandering or elopement event occurs, it is hopefully quickly resolved without police or ambulance involvement. However, if the person goes missing, cannot be redirected, causes a car accident, or becomes assaultive, law enforcement and emergency responders are called upon.

Every county in New Jersey participates in Project Lifesaver. Managed through the county sheriff offices, Project Lifesaver employs a radio transmitter worn around the wrist or ankle. It is tracked if the person wanders. Staff is trained in dementia behaviors, communication and crisis intervention. Each month, a person from the sheriff's office visits the person at home, changes the transmitter's battery, and tests it for functionality.

Project Lifesaver consists of a one-ounce battery-operated radio wrist transmitter emitting an automatic tracking signal every second, 24 hours a day. The signal is tracked on the ground or in the air over several miles. As each wristband has a unique radio frequency, the Project Lifesaver search team positively locates and identifies the person who has wandered away from home or a care facility. Members of the Project Lifesaver team are specially trained, not only in use of the electronic tracking equipment, but especially in the methods to communicate with a person who has Alzheimer's disease or a related disorder. Locating the individual is only part of the mission. The person who is located will be disoriented, anxious, and untrusting. The Project Lifesaver team knows how to approach the person, gain their trust and put them at ease for the trip home.⁷³

The Alzheimer's Association cites that six out of 10 people living with Alzheimer's disease will wander from their home or caregiving facilities.⁷⁴ The Silver Alert System was signed into law in New Jersey in 2009 to help locate missing persons suffering from dementia or other cognitive impairments. The program is a voluntary, cooperative effort between State and local law enforcement agencies and the media.

Driving and car access: Older adult driving is another concern that affects communities. The risk of being injured or killed in a motor vehicle crash increases as a person ages. Yet for most people, driving represents freedom, control and independence, but it relies on many elements of cognition and is a complex skill. It can also be compromised by changes in an individual's emotional, mental and cognitive conditions. Areas with low access to public transit or “senior” buses have higher risk of driving incidents due to people with dementia continuing to drive.

⁷³ Excerpt from the Salem County Sheriff's Department information sheet, accessed 11/4/15 at <http://www.salemcountysheriff.com/wp-content/uploads/2014/03/Project-Lifesaver-Information.pdf>.

⁷⁴ http://www.alz.org/news_and_events_14004.asp

An ongoing debate in New Jersey, as well as many other states, involves when, if, and how to deny access to driving. Currently, the Motor Vehicle Commission has a process for families, doctors, emergency departments, judges, and police officers to request a reassessment of the person's ability to drive by the Commission's Medical Review Board⁷⁵. However, the driver has the right to know who requested the review, which can result in family difficulties or reluctance to report.

A community action guide on cognitive aging from the Institute of Medicine⁷⁶ points to certain actions that communities can take, from distributing information on driving assessment tools and driving courses, to making communities more pedestrian-friendly, and enacting policies to make driving safer. The National Institutes of Health has reported that the rate of crashes among older adults is down in recent years. Credited are a number of factors such as safer cars and safer roads and the ability of older drivers to self-police.

First responders: For years, the Alzheimer's Association has provided training on dementia to first responder groups, such as police, fire departments, and ambulance corps. Training includes communication skills, recognizing dementia, telling dementia from delirium (which may need evaluation in a hospital) or mental illness, supporting caregivers, handling driving situations, basic home safety, and community resources. An emergency responder during a training evaluation commented:

Training emergency responders on dementia is paramount, it not only leads to improved communication between the responder and the person with dementia but ultimately could even save lives.⁷⁷

The Alzheimer's Association Delaware Valley Chapter Safety Department trained 723 emergency responders in the South Jersey region in the past five years. A variety of organizations and emergency responders were trained in settings ranging from state emergency management conferences to smaller departmental roll-call trainings. The audience ranged from emergency managers, law enforcement, fire/EMS (emergency medical services) personnel to disaster volunteers such as medical reserve corps volunteers.

Disaster preparedness: The Governor of New Jersey has the overall responsibility for Emergency Management activities in the State. On behalf of the Governor, all activities and departments are coordinated, directed, and controlled from the NJ Office of Emergency Management (NJOEM) Emergency Operations Center. NJOEM works closely with its federal, State, and local partners to prepare for virtually all hazards, natural or manmade, that could affect New Jersey's families, communities, and businesses.

⁷⁵ New Jersey Motor Vehicle Commission Medical Review Board information page, accessed 11/4/15 at http://www.state.nj.us/mvc/Violations/suspension_medical.htm.

⁷⁶ Cognitive Aging: An Action Guide for Communities, p.3. Institute of Medicine of the National Academies. Accessed 8/12/15 at http://www.iom.edu/~media/Files/Report_Files/2015/Cognitive_aging/Online_Resources_for_Older_Adult_Driving_V2.pdf.

⁷⁷ Quote from a training evaluation by an emergency responder.

DHS is an important NJOEM partner since the Department services at least one in four residents in one way or another, including many with special needs. As a result, DHS must be always prepared and have plans in place. The DHS Office of Emergency Managements (DHS OEM) regularly meets with the NJOEM and constantly monitors the National Weather Service, National Hurricane Alert System, FEMA, the Department of Homeland Security, the NJ State Police, and other public safety, emergency, and first responder agencies.

Many community members can benefit from specialized preparedness plans and need additional assistance if there is an emergency. They may have disabilities; chronic medical conditions; lack transportation; be elderly; be unaccompanied children; come from other cultures; have limited English proficiency or non-English speaking; or be transportation disadvantaged. People with dementia and their families require such special support.

While others can shelter in place with proper supplies for extended periods, a person with dementia may try to leave the home, become excessively frightened by weather, sounds, or power outages. The caregiver is also left without relief. If evacuation is required, this breaks the routine upon which a person with dementia often relies. Suddenly there are unfamiliar places, people, foods, and much more. Simply having basic care items, such as incontinence supplies and medications, is a challenge for anyone with healthcare conditions; it can be devastating for people with Alzheimer's.

The NJOEM uses the National Response Framework definition of "functional needs" because a function-based definition, instead of the "special needs" label, reflects the capabilities of the individual, not the condition, label or medical diagnosis. Before, during, and after an incident, there are the following concerns for individuals with access and functional needs areas:

Maintaining independence - Individuals requiring support to be independent in daily activities may lose this support during an emergency or a disaster. This support may include supplies, durable medical equipment, and attendants or caregivers.

Communication - Individuals who have limitations that interfere with the receipt of and response to information will need that information provided in methods they can understand and use. They may not be able to hear verbal announcements, see directional signs, or understand how to get assistance all because of hearing, vision, speech, cognitive, or intellectual limitations, and/or limited English proficiency.

Transportation - Individuals who cannot drive or who do not have a vehicle may require transportation support for successful evacuation.

Supervision - Before, during, and after an emergency individuals may lose the support of caregivers, family, or friends or may be unable to cope in a new environment (particularly if they have dementia, Alzheimer's or psychiatric conditions such as schizophrenia or intense anxiety).

Medical care - Individuals who are not self-sufficient or who do not have adequate support from caregivers, family, or friends may need assistance.

The NJOEM is committed to whole-community planning: emergency planning that involves entire communities and not just government agencies. By including the full spectrum of people and organizations represented in a community, emergency planning will account for the needs of all communities' members, regardless of their personal circumstances or abilities. Whole-community planning is something the NJOEM practices as a normal course of business, because every life matters.

New Jersey offers *Register Ready*, a confidential registry that allows residents with access and functional needs and their families, friends and associates an opportunity to provide information to emergency response agencies, so emergency responders can better plan to serve them in a disaster or other emergency. In addition, basic disaster preparedness planning tools can help citizens whenever a disaster or emergency situation arises, such as:

- Making set plans for sheltering in place and for evacuation;
- Having supplies, including medication; and
- Having activities handy to meaningfully occupy the person with dementia. These activities should preferably not require electricity, or should have an extended supply of batteries.

Recommendations by the Commission

After reviewing the research, survey input, and public testimony, the Commission recommends the following goals and objectives. The strategies are opportunities noted by the Commission for meeting the goals and objectives:

Goal 1: Increase public awareness of the difference between “normal” cognitive aging and Alzheimer's disease and related dementias.

Objective: Explain the distinction between normal brain changes associated with aging and disease.

Strategy: Promote the messages through partnerships, including the Alzheimer's Association, Alzheimer's NJ, AARP, American Stroke Association, NJ Department of Health, Area Agencies on Aging, medical community and professional/trade associations, and other advocacy/information groups to increase community and family awareness of resources, including the Alzheimer's Association 24/7 Help Line and NJ 2-1-1.

Strategy: Develop more electronic links within existing sister State agency websites, ranging from the NJ Departments of Human Services and Health to the NJ Department of Banking and Insurance to the NJ Department of Transportation, to ensure that reliable information on Alzheimer's disease is available through these trustworthy sources.

Strategy: Engage non-traditional outreach organizations, such as private sector companies, faith-based communities, senior centers, libraries, and retirement communities, to expand the reach of public awareness efforts.

Objective: Increase the availability of information to residents with Alzheimer's disease, family caregivers and professionals about services and supports.

Strategy: Work with public and private partners to ensure that resources are available throughout the state, including private pay options, are known especially for family members for those at risk about the earliest symptoms.

Strategy: Target communications about the special impact of Alzheimer's disease on minority populations, the increased prevalence of dementia in individuals with Down syndrome and individuals living with early-onset Alzheimer's who are under age 65.

Strategy: Encourage public and private employers to offer information to employees on dementia and on the available services and service providers to help affected individuals and their caregivers.

Objective: Develop the infrastructure to support on-going planning and discussion among stakeholders for the coordination of a public awareness campaign.

Strategy: Partner with the Alzheimer's Association; Alzheimer's NJ; NJ Department of Human Services (Divisions of Aging Services, Medical Assistance and Health Services, Disability Services, and Developmental Disabilities); NJ Department of Health; NJ Hospital Association; Home Care Association of NJ; LeadingAge; NJ Adult Day Services Association, and all other relevant entities.

Strategy: Facilitate the flow of information among government agencies, stakeholders and other entities to keep the public knowledgeable about Alzheimer's disease and available resources in the community as well as the importance of advanced health care, long-term care and financial planning.

Goal 2: Expand support for unpaid caregivers of persons with Alzheimer's disease.

Objective: Promote and link caregivers to resources in the local community for help in understanding Alzheimer's disease, learning about support programs, and navigating the long-term care system and financial planning.

Strategy: Identify existing opportunities of organizations with expertise in Alzheimer's disease to inform, educate and offer caregiving strategies and interventions to empower family members and/or friends of those living with Alzheimer's disease.

Strategy: Ensure that there are culturally and linguistically appropriate educational and training tools for families and caregivers and they are widely available.

Strategy: Make sure that the aging and disability networks are aware of and promote existing training materials available to family caregivers.

Strategy: Partner with faith-based organizations to engage volunteers that can reach out to caregivers and provide support in their populations.

Strategy: Provide in-person, phone and web-based support for caregivers through existing channels, such as the Care2Caregivers hotline provided by Rutgers University Behavioral Health Care and the Alzheimer's Association 24/7 Hotline.

Strategy: Enhance NJ 2-1-1's ability to be an effective way for people seeking access to resources related to Alzheimer's disease by ensuring the system has the necessary information on a statewide basis and that it is regularly updated.

Strategy: Explore the possibility with businesses and other workplace sites of creating access to respite care services for usage during an emergency or on a short-term immediate basis.

Objective: Build strong partnerships with the health care community and develop opportunities to promote caregiving as a health risk factor so that health care professionals acknowledge and address the issue.

Strategy: Work with appropriate State agencies and professional trade associations to outreach and educate the workforce that cares for people with Alzheimer's disease, including but not limited to primary care physicians; specialists such as neurologists, geriatricians, and psychiatrists; registered nurses and advanced practice nurses; community health workers; social workers; psychologists; pharmacists; dentists; allied health professionals; and direct care workers like home health aides and certified nursing assistants.

Strategy: Educate family members drawing upon the guidance of the Alzheimer's Association and Alzheimer's NJ about how to educate and reinforce with health care providers on the importance of addressing the needs of caregivers who are caring for individuals with Alzheimer's disease.

Objective: Sustain the array of long-term care supportive services currently offered by the State that provide direct care for individuals with Alzheimer's disease, but also support for caregivers.

Strategy: Maintain the programs funded with State and NJ FamilyCare funding, including the Statewide Respite Care Program, the Adult Day Services Program for Persons with Alzheimer's Disease or Related Disorders, and Managed Long Term Services and Supports (MLTSS).

Strategy: Consolidate five of the nine State-funded Community Based Senior Programs (Home Care Expansion, Alzheimer's Adult Day Services Program, Jersey Assistance to Community Caregiving, Supplemental Home Delivered Meals, Statewide Respite Care Program, and Safe Housing and Transportation) to provide older adults at risk of nursing home placement and spend down to Medicaid with a consumer-directed home and community-based service alternative to institutionalization.

Strategy: Explore options with the ADRCs to maximize support for caregivers through Older Americans Act Title III-E funding (National Family Caregiver Support Program).

Strategy: Explore opportunities to update Older Americans Act contracting policies to support consumer-directed cash management plans to assist family and informal caregivers and self-direct the care for their loved ones at home for as long as possible.

Goal 3: Promote the infrastructure for enhanced quality of services within the healthcare system to meet the growing number of people with Alzheimer's disease.

Objective: Evolve the health care system to better serve people with Alzheimer's disease.

Strategy: Review all state contracts providing services to older adults to ensure that they include quality measures specific to the capability of caring for individuals with Alzheimer's disease.

Strategy: Provide input on Alzheimer's disease and other dementia care issues when regulations are being updated and quality improvement projects are being developed in health care facilities.

Strategy: Maintain New Jersey's participation in the National Partnership to Improve Dementia Care, a public-private coalition with the national goal of reducing the use of anti-psychotic medications in nursing facilities.

Strategy: Build strong partnerships with the health care community and develop avenues for reaching physicians and others in health care on best practices and emerging issues in the treatment and support for individuals with Alzheimer's disease.

Strategy: Promote the usage of the dementia care practice recommendations developed by the Alzheimer's Association and other groups to make providers more aware of them and to encourage utilization.

Strategy: Encourage dementia-informed hospital policies and procedures so that hospitals are prepared to serve individuals with dementia, from emergency room treatment to in-patient hospitalizations.

Objective: Increase the number of health care professionals that will be necessary to treat the growing aging and Alzheimer's populations.

Strategy: Maintain support for the Graduate Medical Education (GME) program, an initiative that leverages federal Medicare dollars to maximize the subsidy available to offset the costs incurred by those facilities that are taking the lead in educating the next generation of New Jersey's doctors.

Strategy: Sustain the New Jersey Action Coalition's long-term care nurse residency program that is working to prepare newly licensed nurses for a growing geriatric population and is led by faculty at Rutgers University, in partnership with the New Jersey Hospital Association, the Health Care Association of New Jersey, and approximately 20 other participating facilities.

Strategy: Engage the state's four medical schools, Cooper Medical School of Rowan University, Rowan University School of Osteopathic Medicine, New Jersey Medical School of Rutgers University, and Robert Wood Johnson Medical School of Rutgers University, on the importance of medical students who specialize in geriatrics and practice in New Jersey.

Objective: Develop the capacity of the health care system to meet the growing number and needs of those with Alzheimer's disease.

Strategy: Foster collaborative efforts among state agencies, long-term care facilities, home and community-based service providers to increase the capacity of the long-term care system to serve individuals with Alzheimer's disease.

Strategy: Ensure that NJ FamilyCare managed care organizations are able to provide dementia-capable services to meet the needs of their NJ FamilyCare members with Alzheimer's disease and other dementias, not only considering older adults but also the younger-onset population.

Strategy: Foster the creation of innovative initiatives like the Statewide Clinical Outreach Program for the Elderly (S-COPE), a program that targets older adults in a long-term care setting who may suffer from mental illness and dementia.

Strategy: Support use of emerging health care models such as the Accountable Care Organizations as a means to integrate and coordinate dementia care within primary care practices and in community health centers with growing populations of older adults.

Objective: Promote training opportunities to better prepare health care professionals to deal with individuals with Alzheimer's disease.

Strategy: Work with the licensing boards to promote continuing education on Alzheimer's disease and other dementias as part of license renewal for doctors, nurses and other health professionals.

Strategy: Foster collaborative efforts between the Alzheimer's Association and key stakeholder groups that are already addressing health care workforce issues, including the NJ Health Care Talent Network, the NJ Nursing Initiative, Health Care Workforce Council and the John J. Heldrich Center for Workforce Development.

Strategy: Collaborate with the professional and trade associations to develop an Alzheimer's disease education program using continuing education credits for health care professionals.

Strategy: Develop strategies to train professionals who provide services to persons with mental illness and developmental disabilities to recognize and address Alzheimer's disease with their consumer populations.

Strategy: Support innovative programs such as the modules offered by the New Jersey Geriatric Education Center that cover the inter-professional approach to assessment and management of Alzheimer's disease and dementia.

Strategy: Recommend educational training for all DHS staff associated with any of the NJ FamilyCare and state-funded programs, as well as training for contract staff who have a primary role of interacting with older adults, their family and or/caregivers.

Goal 4: Improve public safety and address the safety-related needs of those with Alzheimer's disease living in the community.

Objective: Promote safe driving given that changes in physical, emotional, mental, and cognitive conditions can affect an individual's ability to drive safely and the numbers of affected residents is expected to continue growing.

Strategy: Work with the NJ Department of Transportation to help educate the general public on the Silver Alert program.

Strategy: Coordinate with the NJ Department of Transportation's Division of Highway Traffic Safety on its community safety programs involving older drivers with regard to Alzheimer's disease and other dementias.

Strategy: Enhance public awareness of the independent safe driving courses and assessments promoted by the NJ Motor Vehicle Commission⁷⁸ and promote its *Wisdom Behind the Wheel* program designed to help mature driver remain safe on the road.

Strategy: Lend support to state and local efforts to make communities more accessible for walking and the usage of public transportation.

Objective: Educate the public safety workforce about the medical and behavior issues of individuals with Alzheimer's disease so these professionals are better able to assist in an emergency involving these individuals and their families. Offer programs that cover wandering, driving, abuse, neglect, and disaster response.

Strategy: Work with the New Jersey Department of Health to reach out to New Jersey's EMS system, including first responders, emergency medical technicians (EMTs), paramedics, nurses, and physicians, to ensure that they are familiar with the unique aspects of Alzheimer's disease and the best approach to respond to affected individuals.

Strategy: Promote training opportunities with the State's Department of Law & Public Safety to make sure that law enforcement is equipped to manage the unique safety challenges of persons with Alzheimer's disease and other dementias, ranging from wandering to erratic driving, false reports and victimization.

Objective: Ensure that the state's current disaster preparedness plans address the safety of persons with Alzheimer's disease and other dementias as a vulnerable population as is recommended in the *New Jersey State Strategic Plan on Aging, 2013-2017*.

Strategy: Integrate special strategies within the New Jersey DHS Office of Emergency Management (OEM) disaster preparedness plans that specifically address the safety of persons

⁷⁸ For more information, see the New Jersey Motor Vehicle Commission's website at <http://www.state.nj.us/mvc/Licenses/MatureDrivers.htm>.

with Alzheimer's disease and other dementias. This department's OEM regularly meets with the NJOEM and constantly monitors the National Weather Service, National Hurricane Alert System, FEMA, the Department of Homeland Security, the NJ State Police, and other public safety, emergency, and first responder agencies. Then it sees that preparations are in place, then implemented, at all affected facilities in an emergency - so that consumers and staff are not in harm's way.

Strategy: Work with NJOEM to explore and then promote through the local chapters of the Alzheimer's Association and other groups the other state resources that could be tapped to serve residents with Alzheimer's disease. For example, the state offers *Register Ready*, a confidential registry that allows residents with access and functional needs and their families, friends and associates an opportunity to provide information to emergency response agencies, so emergency responders can better plan to serve them in a disaster or other emergency.

Objective: Support and strengthen community programs that provide consistent contact and outreach.

Strategy: Recommend that NJ 2-1-1 has a cadre of community resource specialists who are trained in the unique aspects of communicating with an individual with Alzheimer's disease and are familiar with the burden of Alzheimer caregiving to address caregivers and their special challenges.

Strategy: Increase training for Adult Protective Services workers in New Jersey's 21 counties on Alzheimer's disease and other dementias.

Strategy: Team up with the ADRCs to increase safety awareness for individuals with Alzheimer's disease and encourage local partnerships with law enforcement and seniors and community groups. For example, in Monmouth County, the ADRC operates the Senior Safety Initiative with the Sheriff's Office that uses technology to find persons with Alzheimer's disease or other dementias who wander and become lost.

Goal 5: Support legal protections for, and legal issues faced by, individuals with Alzheimer's disease.

Objective: Promote advance care planning and financial planning so that individuals have the information in the early stage of the disease process to better ensure that wishes are known and then met.

Strategy: Encourage health care provider and community agency education to increase the widespread use of advanced health directives.

Strategy: Increase public awareness of the state-approved forms for advance planning, including the proxy directive, the instruction directive and the Practitioners Orders for Life-Sustaining

Treatment (POLST) form, that are available at no cost via the NJ Department of Health's website⁷⁹.

Strategy: Engage the legal community, from the legal assistance programs at the AAAs/ADRCs to elder care attorneys, to better inform them of the challenges of dementia and the legal services that may be needed by individuals living with the disease as well as their families.

Objective: Support efforts on detecting, addressing and preventing fraud, abuse, neglect and self-neglect of persons with dementia.

Strategy: Collaborate with elder abuse prevention organizations, including Adult Protective Services and the Office of the Ombudsman for the Institutionalized Elderly, to ensure awareness of risks to individuals with Alzheimer's disease and how to safeguard them from abuse.

Strategy: Maintain support for the Office of the Public Guardian and its work to resolve medical, financial, contractual, and social issues for residents suffering from dementia.

Objective: Reduce risk and level of harm created by the economic abuse of persons with Alzheimer's disease.

Strategy: Communicate with financial institutions by working with the Department of Banking and Insurance (DOBI) to develop and implement a consumer awareness plan aimed at financial institutions with branches in New Jersey with regard to the risks of financial exploitation.

Strategy: Work with the Alzheimer's Association and Alzheimer's NJ to integrate the prevention of the exploitation of persons with Alzheimer's disease and other dementias into the *Fighting Fraud* initiative sponsored by the New Jersey Division of Consumer Affairs. Reducing elder fraud is a primary objective of this initiative.

⁷⁹ <http://www.state.nj.us/health/advancedirective/index.shtml>

Appendix A

Sample Survey Question

Information Topics Desired (Question Eight): "What type of information/training would you like to have available to you?"

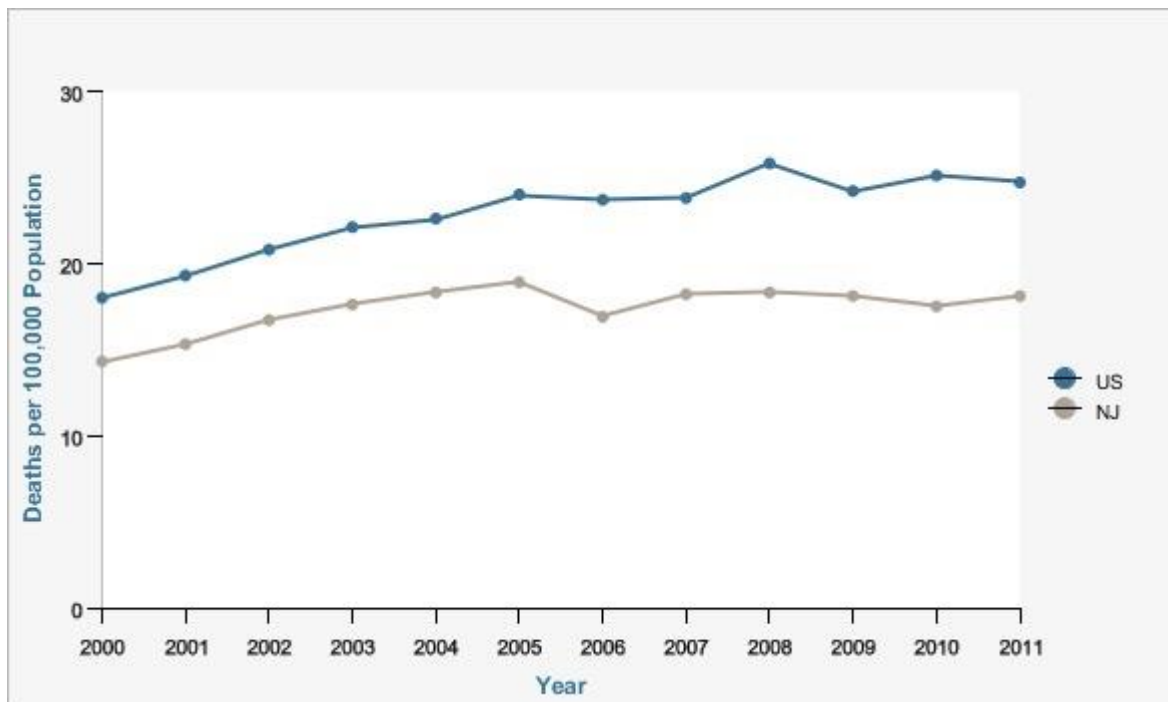
This question allowed participants to note the choices that applied. Responses clustered into two main categories. The first focused on care of the person with Alzheimer's disease: 71.36% would like additional information on resources to assist them in caring for someone with Alzheimer's disease and 65.33% desired more information on caregiver issues. In the second cluster, more information was requested about behaviors exhibited by someone with Alzheimer's disease (72.11%), and disease progression/stages (60.80%). The table below shows the responses to this question:

Answer Choices	Responses
Diagnosis (e.g. physician accessibility, biomarkers, types of dementia, etc.) (1)	54.52% 217
Behaviors (cognitive, psychiatric, social and emotional responses to decline) (2)	72.11% 287
Safety (e.g. wandering) (3)	47.49% 189
10 Warning Signs of Alzheimer's (4)	47.49% 189
Early stage services (5)	47.74% 190
Progression/Stages (e.g. early, middle, late) (6)	60.80% 242
Medication (7)	51.76% 206
Resources (e.g. financial, legal, ethical, behavioral, early/middle/late stage care planning, education and support, etc.) (8)	71.36% 284
Driving and Driving Assessments (9)	24.12% 96
Advocacy and Public Policy Initiatives (10)	36.68% 146
Research Advances (11)	51.26% 204
Cultural Sensitivity (12)	21.86% 87
Person-centered care (13)	40.45% 161
Caregiver Issues (e.g. coping strategies, family dynamics) (14)	65.33% 260
Spirituality (15)	16.08% 64
Availability of Training Options (16)	33.17% 132
Total Respondents: 398	

Appendix B

Demographics

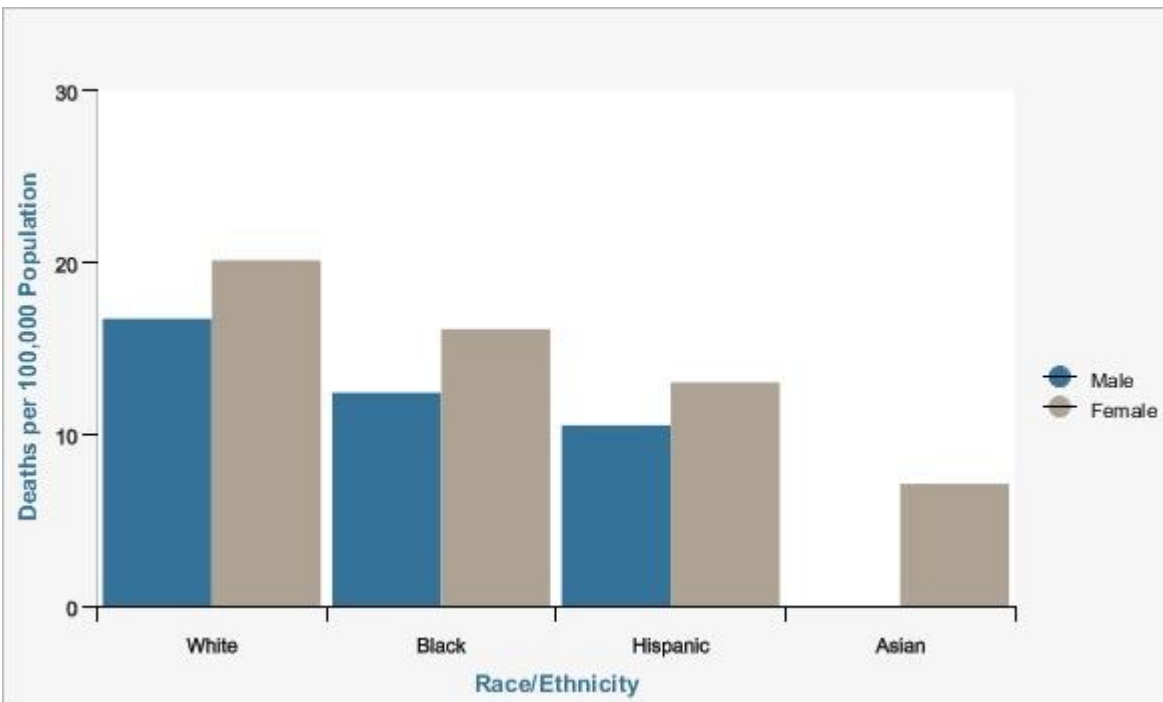
Age-Adjusted Death Rate due to Alzheimer's Disease by Year, New Jersey and the United States, 2000-2011



Data Sources

- Centers for Disease Control and Prevention, National Center for Health Statistics. Compressed Mortality File. CDC WONDER On-line Database accessed at <http://wonder.cdc.gov/cmfi-icd10.html>
- Death Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health
- Population Estimates, State Data Center, New Jersey Department of Labor and Workforce Development

Age-Adjusted Death Rate due to Alzheimer's Disease by Race/Ethnicity and Sex, New Jersey, 2009-2011



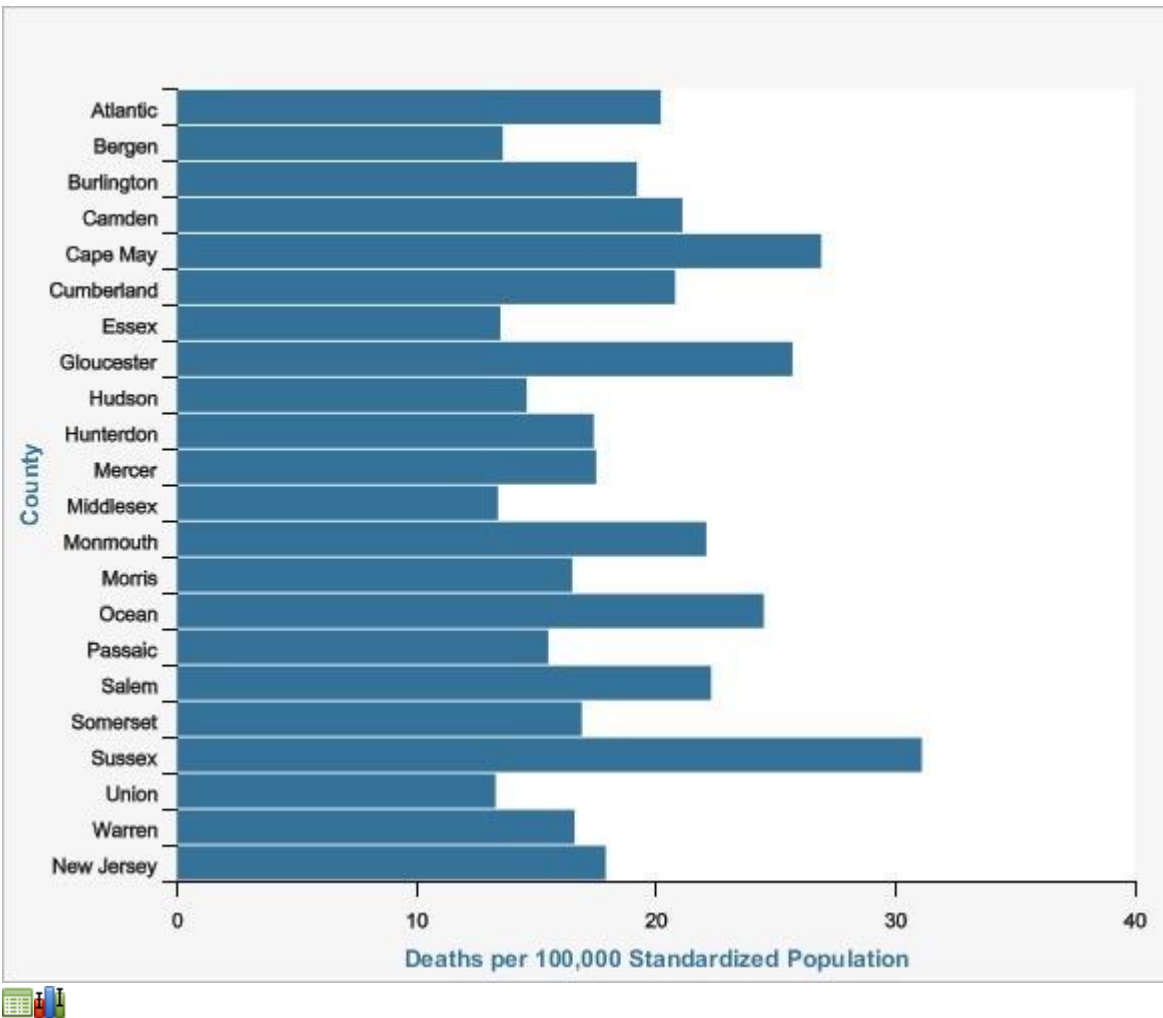
Data Notes:

Data for White, Black, and Asian do not include Hispanics. Hispanic ethnicity includes persons of any race. No rate is shown for Asian males because there are too few deaths to calculate a reliable rate.

Data Sources:

- Death Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health
- Population Estimates, State Data Center, New Jersey Department of Labor and Workforce Development

Age-Adjusted Death Rate due to Alzheimer's Disease by County, New Jersey, 2009-2011



Data Sources

- Death Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health
- National Center for Health Statistics and U.S. Census Bureau. Vintage 2013 bridged-race postcensal population estimates. http://www.cdc.gov/nchs/nvss/bridged_race.htm as of June 26, 2014.