

# MAKE A PLAN FOR ALZHEIMER'S

FINAL REPORT AND RECOMMENDATIONS

DECEMBER 12, 2011



A project of West Virginia Community Voices, Inc.  
Funded by the Claude Worthington Benedum Foundation



## INTRODUCTION

The present and future impact of Alzheimer's disease and related dementias in West Virginia demands the implementation of solutions directed at improving quality of care; the training and awareness of healthcare providers, families and the public; and, fostering research into all aspects of the disease. Our state cannot take this pressing charge lightly, and its ultimate success depends on partners at the state, regional and community-level working collaboratively.

The Make a Plan (MAP) for Alzheimer's initiative seeks to bring together stakeholders to study the issues, draft a state plan for Alzheimer's, and then advocate for its statewide adoption. This initiative is chaired by the Alzheimer's Association, West Virginia Chapter and facilitated by the West Virginia Partnership for Elder Living. This report (the MAP) constitutes the achievement of an important phase of the initiative: the presentation of a unifying set of ambitious, but achievable recommendations for beginning to address the burden of Alzheimer's in West Virginia.

## WORKING GROUP MEMBERS

*We recognize and thank the members of the three MAP working groups and their organizations for their contributions of time, data, information and analysis. With these recommendations and working together as a partnership, we can improve the lives of West Virginians with Alzheimer's, their families, and their communities.*

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## ALZHEIMER'S IN WEST VIRGINIA

Different types of conditions and diseases that result in damaged brain cells or connections between brain cells can cause dementia. Alzheimer's disease is the most common form of dementia, but other forms include vascular dementia, frontotemporal dementia, and Creutzfeldt-Jakob disease. Although meaningful differences exist between the forms of dementia, in many instances the needs of the person are similar. Because Alzheimer's is the most common form of dementia, the MAP focuses on Alzheimer's and uses the term "Alzheimer's" or "Alzheimer's disease," but where appropriate the use of this terminology also is meant to encompass other forms of dementia.

Alzheimer's disease is a neurodegenerative disease that progressively breaks down the functions of the brain. Alzheimer's results in memory loss, loss of ability to communicate, and is fatal. Despite decades of research and billions of dollars, no cure for Alzheimer's exists.

Alzheimer's shares similar risk factors as stroke and cardiovascular illness, including smoking, high cholesterol, obesity, and diabetes. West Virginia consistently reports among the highest rates in the nation for all these risk factors.

According to the Alzheimer's Association's, 44,000 West Virginians age 65 and older have Alzheimer's, and an additional 4,000 individuals under age 65 have younger-onset Alzheimer's. The number of West Virginians with Alzheimer's is expected to rise dramatically as the state's more than 500,000 baby boomers reach age 65 and enter the age period of greatest risk for developing Alzheimer's. Our state faces an impending wave of new diagnoses and new families who will face the devastating, debilitating and heartbreaking disease known as Alzheimer's.

In West Virginia in 2008, 662 death certificates for West Virginia residents were filed with Alzheimer's disease coded as the underlying cause of death. This accounted for roughly one out of every 32 deaths to West Virginians that year and was the state's eighth leading cause of death. In that same year, dementia was the state's fifth leading cause of death. Together deaths from Alzheimer's disease and dementia constituted the state's fourth leading cause of death in 2008.

People with Alzheimer's need some degree of care throughout every stage of the disease; eventually requiring around-the-clock supervision and care. A variety of care systems are needed to meet the needs of people with Alzheimer's, including nursing facility, assisted living, hospice, adult day, and respite care. (A glossary of care and support services is included at the end of this report.) For both paid and lay caregivers, the unique challenges presented by Alzheimer's require not only patience, but a significant understanding of the disease and caregiving best practices.

The Alzheimer's Association reports that approximately 70 percent of individuals with Alzheimer's disease and related dementia live at home and receive care from family and friends. In 2010, 105,464 Alzheimer caregivers in West Virginia provided 120,102,716 hours of unpaid care. The economic value of this care was valued at an astonishing \$1,432,825,396.

The remainder of people with Alzheimer's resides in long-term care settings including nursing facilities and assisted living. The Alzheimer's Association estimates that 70 percent of nursing facility residents have some degree of cognitive impairment, including Alzheimer's. Additionally, the West Virginia Health Care Authority reports that in 2009, Medicaid paid for approximately 75 percent of patient days in skilled nursing facilities, while Medicare paid for only about 12 percent of patient days.

Clearly, Alzheimer's affects every West Virginian, either as a person living with Alzheimer's, a family member, a friend, an employer, or simply a taxpayer. As a result, the development and execution of a comprehensive state plan to address Alzheimer's will benefit all West Virginians.

## THE MAP PROCESS

The Make a Plan (MAP) for Alzheimer's initiative kicked off in February 2011 with an event at the West Virginia State Capitol. More than 30 organizations participated in this event, which was hosted by the Partnership for Elder Living and the Alzheimer's Association, West Virginia Chapter.

Meanwhile, during the 2011 Legislative Session, the Legislature approved Senate Concurrent Resolution (SCR) 38 (see Appendix), which called for a "study of the needs, challenges and issues facing West Virginians with Alzheimer's disease and their families for the purpose of making recommendations on how the State of West Virginia can better assist them in getting the care, research, support and treatment they deserve." This important action established the Legislature as a strong supporter of the development of West Virginia state plan for Alzheimer's.

In follow up to the kick-off event and the adoption of SCR 38, three MAP working groups, populated by more than 50 individuals, began meeting to study the key issues and develop potential policy and program solutions. The working groups met on approximately a monthly basis between May and October.

The three working groups were "Care Systems", chaired by Jack Tanner, the Executive Director of the Raleigh County Commission on Aging; "Education and Training", chaired by Dr. Mark Newbrough, a geriatric physician and director of the West Virginia Geriatric Education Center; and, "Research and Quality Improvement", chaired by former Bureau of Senior Services Commissioner Ann Stottlemeyer. The full MAP membership is included in the beginning of this report.

## THE RECOMMENDATIONS

The 20 recommendations that follow constitute the working groups' beliefs of what West Virginia's MAP for Alzheimer's should include. They reflect the thinking of a diverse set of partners and are a product of consensus-driven discussion and analysis. The recommendations are policy-based, and most require strong involvement and leadership from the Legislature and state agencies.

A brief rationale statement follows each recommendation and is intended to provide more detail on why the recommendation is critical. The MAP also identifies the "responsible entities" that must be engaged in order to implement each recommendation. Where the support of the Legislature is needed, it is listed first; followed by state agencies; and then, any private and nonprofit groups.

For each recommendation, the "costs to the state" are labeled as "minimal" (under \$10,000), "moderate" (under \$100,000), "high" (more than \$100,000), or "unknown." The MAP working groups did not conduct detailed fiscal scoring. The costs provided are estimates, and in many cases, an actual figure is not listed as the working groups felt further analysis was needed to ascertain the exact cost.

Finally, each recommendation contains a "timeline" for implementation. The MAP's 20 recommendations cannot be implemented simultaneously, and in some instances, the implementation of certain recommendations depends on the prior implementation of other recommendations. In establishing the timeline, the MAP working groups also presumed that before any implementation can occur, the first step is for the Legislature to adopt or endorse the MAP. Thus, the timeline section measures from the future point at which the Legislature adopts the MAP and uses the labels "short term" (within 2 years), "mid term" (within 4 years), and "long term" (5 years or longer) to identify the sequence for subsequently implementing its 20 recommendations.





## **CARE SYSTEMS**

Care systems are the organizations of people, resources and institutions that provide the services delivering care to people with Alzheimer's disease and their family and lay caregivers. The major categories of care systems for people with Alzheimer's are: acute, home and community-based, and long-term care. These systems are the network provided by our state government, long-term and acute care facilities, and nonprofit social service organizations, along with other entities.

The focus of the Care Systems Working Group was to evaluate the West Virginia care systems in which people with Alzheimer's and their caregivers receives services, as well as their transitions through the various systems throughout the course of the disease. The group strove to identify gaps in current service models, barriers to receiving services for people with the disease and their caregivers, and strategies to best address these issues. The group's goal was to develop realistic recommendations that provide quality, meaningful services to people with Alzheimer's and their caregivers, which enable them to age-in-place to the fullest extent possible or to transition into more intensive types of care with minimal negative effects.

## **Recommendation 1.1**

### **Increase the case mix classification for nursing facility residents with Alzheimer's disease.**

#### **Rationale:**

Each resident of a nursing facility is assigned a “case mix” score. This score is based on a resident’s care needs (“acuity level”). If a resident is a Medicaid member, the case mix score determines how much Medicaid reimbursement a facility may receive for the resident’s care. Medicaid pays for approximately 75 percent of nursing facility patient days in West Virginia annually.

Nursing facilities in West Virginia receive lower levels of Medicaid reimbursement for the care of residents with Alzheimer’s because they typically do not have high acuity levels. The current reimbursement levels do not reflect the fact, however, that residents with Alzheimer’s often require extra staff time because of behavioral issues in the early and mid-stages of the disease and because of the need for greater assistance with activities of daily living at the end stage of the disease.

Alzheimer residents with severe behavioral issues also may be discharged because the nursing facilities cannot accommodate their needs under the current system of reimbursement, and families may have no choice but to move loved ones to a facility farther away. A 2010 West Virginia Partnership for Elder Living Roundtable on Behavior-Related Exits from Long-Term Care, found that in some instances families report having to place their loved one in a facility in a neighboring state, such as Ohio.

Quality care is the goal in any nursing facility and people with Alzheimer’s deserve such care. At the same time, facilities deserve realistic reimbursement to provide this care. Appropriate reimbursement will support and include specific staff training for better service delivery.

The case mix weight for the following classes should be increased for nursing facilities as follows:

Impaired Cognition B (Class 20) 3.6

Impaired Cognition A (Class 21) 3.1

Challenging Behaviors (Class 22) 3.6

Challenging Behaviors (Class 23) 3.1

**Responsible entities:** West Virginia Legislature, Bureau for Medical Services

**Costs to the state:** Unknown at this time; further analysis is needed.

**Timeline:** [SHORT TERM] Within two years of the adoption of Alzheimer’s State Plan.

## **Recommendation 1.2**

**Expand the availability of quality, affordable home and community-based services for individuals with Alzheimer’s disease and their caregivers by increasing funding for the state-funded Family Alzheimer’s In-Home Respite (FAIR) and Lighthouse programs to serve more families statewide and to alleviate waiting lists that frequently exist for both programs.**

### **Rationale:**

While assisted living or nursing facility care at times may be the most appropriate care setting, more than 70 percent of individuals with Alzheimer’s are cared for at home by family members or other lay caregivers, sometimes with very little outside help. Many families prefer to care for their loved ones at home; however, it is not uncommon for caregivers to become physically sicker than the person for whom they provide care. Additionally, two thirds of employed caregivers report having to go to work late, leave early, or take time off due to their caregiving responsibilities.

Caregivers need a break and a little peace of mind. They also may need assistance with bathing, meal prep, and other tasks associated with care of their loved ones. Caregivers who have access to support services and get a regular break are often less likely to become patients themselves and more likely to be better caregivers for a longer period of time. To begin to meet these needs, the West Virginia Legislature created the FAIR program in 2006 and the Lighthouse program, a non-Medicaid personal care program, in 2007. Both programs are fee-for-service and operate on a sliding-fee scale.

These programs have been very successful in assisting people with Alzheimer’s and their caregivers throughout all stages of the disease. Despite receiving funding increases over the last few years, counties often still have waiting lists. Most recently, a significant funding increase in state fiscal year 2012 provided an additional \$1 million dollars for these two programs, bringing funding for Lighthouse and FAIR to a combined annual appropriation of \$11,859,559. With a 25 percent projected increase in the number of West Virginians with Alzheimer’s by 2025, the demand for these programs definitely will continue to grow. Consequently, funding should continue to increase incrementally towards a combined goal for both programs of at least \$20,000,000 annually.

**Responsible entities:** West Virginia Legislature and the Bureau of Senior Services

**Costs to the state:** High. Incremental increases from current funding of \$11,858,559 to \$20,000,000 annually.

**Timeline:** [SHORT TERM] Initial funding increases should begin within one year of the adoption of the Alzheimer’s State Plan.

### **Recommendation 1.3**

#### **Explore the addition of an Alzheimer's Disease Waiver to the spectrum of Medicaid 1915(c) Home and Community-Based Waiver programs offered in West Virginia.**

##### **Rationale:**

Under the umbrella of the Medicaid 1915(c) Home and Community-Based Waiver program, West Virginia presently operates two programs: the Aged and Disabled Waiver and the MR/DD Waiver. The 1915 (c) Waiver program does make other options available to states beyond these two programs for providing long-term care services in-home and community-based settings.

Because of the unique and unpredictable nature of Alzheimer's, individuals with the disease may qualify financially, but not medically (functionally), for the Aged and Disabled Waiver, as well as the non-waiver Medicaid Personal Care program. Despite their frequent lack of eligibility, people with Alzheimer's may require as much or more care than individuals who do qualify, and their family and lay caregivers often are desperate for help.

Creating a new 1915(c) Waiver program specifically for people with Alzheimer's could help meet their needs in an efficient and effective manner. Assisted living and adult day services are two beneficial programs for people with Alzheimer's that currently are not offered by the Medicaid Personal Care program or the Aged and Disabled Waiver. By establishing a new program specifically for people with Alzheimer's, eligibility determinations could focus on cognitive deficits, while services could include options like assisted living, adult day care, and respite care that would address the most pressing needs of people with Alzheimer's and their caregivers.

**Responsible entities:** Bureau for Medical Services

**Costs to the state:** Unknown at this time; further analysis is needed.

**Timeline:** [LONG TERM] Once the Alzheimer's State Plan is adopted, additional analysis time is needed before implementation of the recommendation can occur. This recommendation will require federal approval.

## **Recommendation 1.4**

**Promulgate regulations for licensure of adult day health services and add those services as a reimbursable service in a new Alzheimer’s Disease Medicaid Waiver program.**

### **Rationale:**

Historically, the two most common designs of adult day care programs are the medical model and the social model. The medical model provides comprehensive medical, therapeutic and rehabilitation day treatment. The social model offers supervised activities, peer support, companionship, and recreation. Many other states now have established a “hybrid” form of adult day care services called “adult day health” services that combine aspects of the medical and social models.

Adult day health services offer benefits for the caregiver and the person with Alzheimer’s by providing quality social engagement and some health services to the person with Alzheimer’s, while the caregiver receives respite from demanding caregiving duties. Adult day health services also are a lower cost long-term care support service, often enabling caregivers to keep their loved ones at home longer.

According to a recent national survey by LeadingAge, West Virginia is the only state in the nation with no Medicaid reimbursement for any type of adult day services. Medical model adult day care is regulated by the state, but no medical model day care program operates in West Virginia. Social model day care programs do exist across the state but are not regulated, which leaves individuals in such programs at risk for substandard care. West Virginia does not regulate the hybrid-model adult day health services, and no program operates in West Virginia at this time.

A 2007 West Virginia Adult Day Services Roundtable concluded that the state should replace the medical model regulations with the adult day health hybrid model and establish guidelines. At that time, several existing social model programs indicated they would adapt their programs to fit the hybrid model and apply for licensure. To date, the state has not moved forward in adopting this recommendation.

The majority of adult day care in West Virginia presently is paid for privately and thus, limits utilization of the service across the state. By establishing a reimbursement mechanism for adult day health services through the Medicaid program, providers would have a financial incentive to offer this service, and more West Virginians would be able to access it.

**Responsible entities:** West Virginia Legislature, Bureau for Medical Services, and the Office of Health Facility Licensure and Certification

**Costs to the state:** Unknown at this time; further analysis is needed.

**Timeline:** [MID TERM] Once the Alzheimer’s State Plan is adopted, additional analysis time is needed before implementation of the recommendation can occur.

## **Recommendation 1.5**

### **Secure state funding for the Alzheimer's Association's 24/7 Helpline.**

#### **Rationale:**

The Alzheimer's Association, West Virginia Chapter is the only voluntary health organization in the state dedicated to providing education and support to people with Alzheimer's disease, their families, and their caregivers. The 24-hour Helpline is operated by trained staff members who understand the disease, its progression, and how it affects the physical and emotional health of people with Alzheimer's, as well as their families and caregivers.

The Helpline is a free service to users and can provide consultations with mid-level clinicians who provide crisis assistance and education on dealing with issues and problematic behaviors in the moment. It also provides referrals to other programs and services. In surveys, West Virginia Helpline users described the contact as being very helpful and improving their knowledge of the disease and caregiving skills.

A recent study, conducted both in Britain and Australia, found that the perceived severity of the burden of being an Alzheimer caregiver was determined by how alone or trapped the caregiver felt. Other studies indicate that knowing help is a phone call away, knowing there is no fee for the service, and hearing a knowledgeable and comforting voice on the phone all help to ease the caregiving load.

A study conducted in Ohio in 2002, as a joint project between the Cleveland Area Alzheimer's Association and the managed care company Kaiser Permanente, concluded that the Helpline call interaction had positive results. The study found that for caregivers calling the Helpline, the average number of emergency department visits and hospital admissions for the individual with Alzheimer's decreased, and the incidence of caregiver depression declined.

**Responsible entities:** West Virginia Legislature and the Alzheimer's Association, West Virginia Chapter

**Costs to the state:** Moderate. \$45,000 annually to support staffing and operation of the Helpline.

**Timeline:** [SHORT TERM] Within one year of the adoption of the Alzheimer's State Plan.

## **Recommendation 1.6**

### **Create a state-sponsored option for long-term care insurance.**

#### **Rationale:**

Better outcomes at lower costs typically are achieved when families possess the resources and ability to care for people with Alzheimer's disease in community-based settings. Many families find they are unable to keep their loved ones in their communities for as long as they would otherwise choose though because they have not saved enough to provide for necessary in-home support and services.

West Virginia should support policies and programs that encourage saving for long-term care expenses, such as participation in long-term care insurance programs. Most long-term care insurance policies cover both residential and community-based long-term care costs. Consequently, long-term care insurance can be a critical tool in meeting the financial challenges that accompany Alzheimer's and enable people to reside in the community as long as medically appropriate.

Presently, access to long-term care insurance in West Virginia is limited, either purchased privately or occasionally offered as a benefit by private employers. In 2009, West Virginia enacted legislation creating the Long Term Care Partnership Program. The program would allow an individual to retain assets at the time they apply for Medicaid equal to the dollar amount previously paid out under the individual's private long-term care insurance policy. Final program regulations have not been issued. This program needs to be promoted once it is operational.

Still, many individuals are unaware that such policies are even available or unable to afford the monthly premiums at their present cost. West Virginia should explore establishing its own state supported long-term care insurance program in order to improve West Virginians' access to quality, affordable long-term care insurance.

**Responsible entities:** West Virginia Legislature and the Insurance Commission

**Costs to the state:** Unknown at this time; further analysis is needed.

**Timeline:** [LONG TERM] Once the Alzheimer's State Plan is adopted, additional time is needed to study the issue and develop a viable and sustainable model.



### **Recommendation 1.7**

**Implement “Alzheimer-informed” facility policies and procedures to create a system of “Universal Observation” to identify people with Alzheimer’s disease in healthcare settings so that people receive optimal inpatient care, as well as ambulatory medical services.**

#### **Rationale:**

Because people with Alzheimer’s sometimes exhibit only subtle signs of their disorder or may be withdrawn and not very interactive, they frequently are not identified by staff in acute care settings as having cognitive impairments. When impaired persons are not recognized as impaired, they will receive less than optimal care. Acute care providers need to develop “Alzheimer-informed” facility policies and procedures to identify and appropriately treat people with Alzheimer’s in hospitals and neuropsychiatric facilities.

As Universal Precautions have taught providers to treat all bodily fluids the same, regardless if those fluids are known to be infected or not, a system of Universal Observation would ensure that all patients admitted are evaluated by the staff for evidence of needing assistance, whether they are previously known to have Alzheimer’s or not. Thus, for example, if a patient is not eating well, observant staff members would assess the patient to determine if he is not eating because of a medical problem, such as pain, or an environmental problem, such as not having his glasses, or a cognitive problem in which he does not have the capacity to handle eating utensils.

The effect of such a protocol would be that no patient would go without nutrition and the cognitively impaired patient would be identified, whether a diagnosis previously had been entered in the medical record or not. Once recognized, the person with Alzheimer’s could be identified by a subtle, non-threatening, and non-discriminatory method so that all staff who come in contact with the person during his stay would be aware of the deficit.

**Responsible entities:** Office of Health Facility Licensure and Certification, acute care facilities, Alzheimer’s Association, West Virginia Chapter, West Virginia Geriatric Education Center, and the West Virginia Hospital Association

**Costs to the state:** Minimal. Implementation costs likely would be very small, as these changes primarily involve facility and provider attitudinal changes.

**Timeline:** [LONG TERM] Within five years of the adoption of the Alzheimer’s State Plan.

## **Recommendation 1.8**

**Develop a non-threatening, non-discriminatory system to identify people with Alzheimer's disease in acute care settings in order to improve safety and quality of care.**

### **Rationale:**

In addition to the reasoning outlined in the previous recommendation, safety is a key issue for people with Alzheimer's in acute care settings. More than 60 percent of all individuals with Alzheimer's will become lost in familiar surroundings. This risk is heightened when the person is in a new and unfamiliar place and suffering from an acute illness. Often in acute care facilities, such as hospitals, patients are permitted to walk in the hallways, visit other areas of the hospital, and even leave the building to smoke. These allowances could result in catastrophic consequences for both the person with Alzheimer's and the facility.

A pilot project should be supported to test creative solutions for ensuring the safety of people with Alzheimer's in acute care settings. An ideal hospital in which to run the trial would be one with an existing program or special interest in elder care, such as Cabell Huntington Hospital, which has a Nurses Improving Care for Healthsystem Elders (NICHE) program and a dedicated group of Geriatric Resource Nurses. A similar pilot program also could be implemented in a rural hospital that has no specialized programs in order to identify any barriers to implementation and to determine the feasibility of implementation statewide.

The protocols explored could include procedures similar to a system used by some hospitals that identify a patient at risk of falling by posting a picture of a falling star at the head of the patient's bed. For people with Alzheimer's, these systems could include different color hospital gowns, with the color code known only to staff, or perhaps an additional wrist band, also color coded.

**Responsible entities:** Acute care facilities, Alzheimer's Association, West Virginia Chapter, West Virginia Geriatric Education Center, and the West Virginia Hospital Association

**Costs to the state:** Minimal. A small grant of approximately \$5,000 from the state or private source could support this work and pay for a program coordinator to develop and introduce the program to a pilot hospital. Cost of statewide implementation will require further analysis.

**Timeline:** [SHORT TERM] A pilot project could begin as soon as funding is secured.

### **Recommendation 1.9**

**Ensure that program guidelines for the Bureau for Medical Services' chronic disease health homes state plan amendment reflect the unique needs of people with Alzheimer's disease.**

#### **Rationale:**

The West Virginia Medicaid program is in the process of implementing a health homes program for older adults with chronic conditions. Many of the intended participants have or will develop Alzheimer's.

People with Alzheimer's have extensive long-term care needs and unique and often challenging symptoms, including progressive memory loss, potential for challenging behavior, and the eventual loss of the ability to advocate for their own care needs. As a result, a care system such as a health home, which utilizes a care coordinator, can be a good match for a person with Alzheimer's. It is critical that the new health homes program include guidelines for addressing these individuals' very specific needs and recognize the role of surrogate decision makers.

**Responsible entities:** Bureau for Medical Services

**Costs to the state:** Minimal. Implementing these guidelines likely would not increase the overall operational cost of the program.

**Timeline:** [SHORT TERM] Within one year of the adoption of the Alzheimer's State Plan.

## **EDUCATION AND TRAINING**

The Education and Training Working Group evaluated the education and training needs of a wide range of medical professionals, first responders, family members, and other lay people. The group's goal for West Virginia is that all West Virginians who work with and interact with people who have Alzheimer's disease are "Alzheimer capable," meaning they can competently interact, assist and care for people with Alzheimer's disease according to the best practice models of care.

One of the first steps toward meeting the overall goal is ensuring that key health professionals and lay caregivers receive competency-based training. Competency-based training requires more than just attending a training session. It includes an evaluation of learning obtained, such as a post-training test or hands on application of skills learned, in order to demonstrate that an individual possesses the skills and knowledge necessary to meet the standards. Fortunately, several existing quality training programs already operate in West Virginia, and the state can leverage and build upon these programs to help meet the statewide goal.

By investing in education and training programs that increase the supply, distribution and quality of the Alzheimer's care workforce, the state will help improve care and outcomes for people with Alzheimer's and their families.

## **Recommendation 2.1**

**Establish a formal network of providers of Alzheimer training in West Virginia, an “Alzheimer Education Council,” to increase the availability of quality continuing education and other training on Alzheimer’s disease and serve as consultants on the development of competency-based models of Alzheimer training for all levels of providers and caregivers.**

### **Rationale:**

Although several providers offer Alzheimer training across the state, West Virginia does not meet all its training needs. This situation is in part due to lack of capacity and coordination among existing providers, people’s hesitancy to seek out training, and low public and professional awareness of existing training opportunities. The Alzheimer Education Council would guide the development of a quality Alzheimer’s care workforce, including conventional healthcare professionals and paraprofessionals, as well as first responders, county aging providers, housing providers, family and lay caregivers, and other critical workforce professionals.

This Council of professional trainers would work together to establish a core set of Alzheimer competencies and common language that would serve as the basis for standardized Alzheimer training programs for all health, mental health, and social service professions, and family and lay caregivers. The Council would be charged with identifying and prioritizing training needs and methods of delivery. For some categories of learners, training curricula currently available from the Alzheimer’s Association, such as “The Basics of Best Care,” family and lay caregiver, in-home direct care worker, and first responder trainings and the essentiALZ™ dementia certification course, could be implemented in a statewide model with minimal modification.

The Council would partner with higher education institutions and the community and technical colleges to offer Alzheimer education events and encourage the infusion of Alzheimer competencies into curriculum. Council members would host and present at continuing education training opportunities, which are especially important for reaching mid-level providers and physicians with Alzheimer education. Beyond presentations at continuing education conferences, the information could be delivered in the format of resource guides, online libraries, live webinars, and videoconferencing. Topics to cover include diagnosis and early detection and medical and behavioral aspects of Alzheimer’s, as well as referral to social supports, mental health services, end-of-life care, and planning.

Lastly, the Council would oversee the development of a public education campaign on Alzheimer’s to increase visibility and awareness of available resources both statewide and locally and reduce the stigma associated with Alzheimer’s.

In the future, the Council could be replicated or utilized to develop training on other geriatric health topics.

**Responsible entities:** Bureau of Senior Services, community and technical colleges, higher education institutions, Alzheimer's Association, West Virginia Chapter, Blanchette Rockefeller Neurosciences Institute, West Virginia Geriatric Education Center, health profession licensing boards, physician and mid-level provider associations, and other health professional organizations

**Costs to the state:** Moderate. This effort would utilize existing organizations and programs to reduce cost to state. Funding could be used for coordination, materials, staffing, speaker fees, technology, and to develop and execute a public awareness campaign.

**Timeline:** [SHORT TERM] Stakeholders could begin meeting immediately.

## **Recommendation 2.2**

**Establish a state-funded Alzheimer's disease training program for family and lay caregivers to be offered statewide.**

### **Rationale:**

Family and lay caregivers serve as the backbone of our state's long-term care system. The largest current provider of Alzheimer family and lay caregiver training in West Virginia is the Alzheimer's Association. Other entities, such as county aging providers and universities, also offer training, although some are not specific to Alzheimer's. These programs provide a quality training curriculum; however, access and awareness of training opportunities remain limited across the state.

A statewide training model would improve access to quality training by caregivers. The training curriculum would be developed in consultation with existing caregiver trainings offered and with input from the Alzheimer Education Council. The training would be a consistent offering statewide, as well as competency-based.

In order to ensure that caregivers who most need the training are able to access it, an effective program would include funding for outreach, respite care, and adult day services to allow the caregiver to leave the care recipient in a safe environment while the caregiver attends training.

The structure of this program would create invaluable statewide capacity for training. In the future the program could be expanded beyond Alzheimer's to include other training topics that family and lay caregivers require. Additionally, once the basic training is established, it could be modified to include other formats to appeal to a broader array of caregiver needs and learning styles.

**Responsible entities:** West Virginia Legislature, Bureau of Senior Services, Office of Adult Education and Workforce Development, Alzheimer's Association, West Virginia Chapter, county aging providers, West Virginia Geriatric Education Center, and other training providers

**Costs to the state:** High. Requires a state appropriation to fund a new program.

**Timeline:** [SHORT TERM] Within two years of the adoption of the Alzheimer's State Plan.

### **Recommendation 2.3**

**Develop and mandate the inclusion of competency-based Alzheimer’s disease training for direct care workers working in long-term care facilities, acute care settings, and community-based programs.**

#### **Rationale:**

West Virginia does not mandate training about Alzheimer’s for direct care workers across care settings. Direct care workers may be referred to by different names depending on the care setting, such as home care aide, homemaker, or personal care aide.

Direct care workers (as well as most other employees) in long-term care facilities are required to complete two hours of training in Alzheimer’s disease and related dementia within 30 days of beginning employment and another two hours annually. More expansive requirements exist for direct care workers in special care units. West Virginia has approximately 12 special care units, which provide care specifically for people with Alzheimer’s. Special care unit employees must complete an initial 30 hours of training and then eight hours of continuing education training. State regulations mandate the topics that these trainings must cover.

The majority of people with Alzheimer’s, though, are cared for at home. Presently, no Alzheimer training is mandated by the state for most direct care workers in acute care or home-based settings. Many workers employed by county aging providers do receive mandated Alzheimer training as part of their work with the Family Alzheimer’s In-Home Respite (FAIR) program.

Although the current requirements for long-term care settings are commendable, educational outcomes for participants could be further improved by incorporating a program with standardized curriculum, an opportunity for hands on learning, competency testing, and regulation of training providers.

Similar to the model proposed for family and lay caregivers, a statewide training program across care settings is needed. These changes should be implemented so that direct care workers in all care settings receive at least two hours of dementia care training annually, in addition to the training required for new hires. Existing training models such as the Bureau of Senior Services FAIR training and the Alzheimer’s Association’s long-term care facility training offer a solid foundation for any statewide mandate. The Alzheimer Education Council could assist in developing the training curriculum.

**Responsible entities:** West Virginia Legislature, Bureau for Medical Services, Bureau of Senior Services, Office of Adult Education and Workforce Development, Office of Health Facility Licensure and Certification, Alzheimer’s Association, West Virginia Chapter, county aging providers, representatives of care settings, and other training providers

**Costs to the state:** High. Requires a state appropriation to fund a new program.

**Timeline:** [MID TERM] Within three years of the adoption of the Alzheimer’s State Plan.



## **Recommendation 2.4**

**Study the effectiveness to date of the West Virginia Silver Alert program, make recommendations for the future of the program, and determine the Alzheimer education and training needs of first responders.**

### **Rationale:**

According to the Alzheimer's Association, at least six out of 10 people with Alzheimer's disease will wander from their homes or caregiving facilities at some point. If not found within a 24-hour period, up to 50 percent will suffer serious injury or death. Even in one's own neighborhood or a place that is familiar, a person with Alzheimer's may become disoriented and lost.

Because of behaviors associated with the disease and the fact that 95 percent of people who wander are found within one-quarter mile of their last location, searching for a person with Alzheimer's is very different than searching for other people. A variety of search and locator programs do exist to help prevent wandering and assist in incidents where an individual does wander. These programs operate most effectively when first responders (law enforcement, fire, EMT, adult protective services, etc.) receive appropriate training in medical and behavioral issues related to Alzheimer's, caregiver burden, and specific search techniques for people with Alzheimer's.

Presently, first responders receive inconsistent training on Alzheimer's. The state should ensure that all first responders receive training on communicating with people with Alzheimer's and dealing with behaviors, as well as working with family and lay caregivers to help them better understand the disease and where they can access support services.

The West Virginia Silver Alert program was established by the Legislature in 2009 and is designed to locate individuals with cognitive impairments including Alzheimer's. It is modeled loosely on the AMBER Alert™ Program for locating missing children. Now that the Silver Alert program is operational, it needs to be evaluated to explore increasing its public awareness, determine whether it is being over or underutilized, and decide how well it is integrated with other nationwide programs such as Project Lifesaver, Medic Alert® + Alzheimer's Association Safe Return®, and Comfort Zone. These other programs also warrant study to determine how to increase public awareness and use of their services.

**Responsible entities:** West Virginia Legislature, Bureau for Children and Families, Adult Protective Services, Office of Adult Education and Workforce Development, Office of Emergency Management Services, Office of the State Fire Marshall, State Police, Alzheimer's Association, West Virginia Chapter, and Project Lifesaver

**Costs to the state:** Minimal.

**Timeline:** [SHORT TERM] Study could be conducted during 2012 Legislative Interim Sessions.

## **Recommendation 2.5**

**Devise incentives and increase exposure to geriatrics during medical school and residency in order to recruit more physicians and mid-level providers into practicing geriatrics. Ensure adequate reimbursement exists for the services they provide.**

### **Rationale:**

In order to meet the rapidly growing aging population, West Virginia needs to increase the number of physician and mid-level providers with training in geriatrics. The state should explore increased use of available tools, such as tuition assistance, loan forgiveness, housing subsidies, and stipends that encourage healthcare professionals to pursue specializations in gerontology and geriatrics, particularly those providers who make a commitment to work in underserved communities.

In addition to incentive programs, health sciences programs at higher education institutions and the community and technical college system should evaluate how they can effectively incorporate more content on geriatrics into curriculum and clinical training. With an extremely small number of geriatric residents and fellows in the state, primary care medical residency programs also could offer education sessions for residents, to match what they learn in training to what they are observing in their own patients in primary care clinics.

West Virginia currently has very few mental health providers who focus on geriatric populations. Federally qualified health centers do offer cost-based reimbursement for some mental health providers, such as licensed independent clinical social workers, but the majority of older adults receive care in private practice settings. The growing adoption of the health home model, which includes mental health as an integral piece, can assist in establishing more widespread reimbursement both through Medicaid and private insurance for mental health services. As a result, existing mental health providers should be offered incentives to provide this type of care, and newly trained professionals should be offered similar incentives to enter a practice with a geriatric focus.

**Responsible entities:** Bureau for Medical Services, community and technical colleges, higher education institutions, and the Higher Education Policy Commission

**Costs to the state:** Moderate to High. Could expand existing state-funded programs such as the primary care provider-focused Health Sciences Scholarship to include geriatrics in its definition of primary care or develop a new program solely for geriatrics.

**Timeline:** [MID TERM] Within three years of the adoption of the Alzheimer's State Plan.

## **RESEARCH AND QUALITY IMPROVEMENT**

Research about Alzheimer's disease, its causes, onset, and possible cures is in its infancy. Several elements such as the West Virginia Alzheimer's Disease Registry and the collection of Alzheimer-related risk factor and mortality data are in the early stages of development and hold significant potential for expansion and development. Research on quality of care for delivery of services and methods to enhance quality of life for this population, however, is sparse.

The Research and Quality Improvement Working Group reviewed the available research at a national and state level and developed the following recommendations to expand the collection of West Virginia specific information, and in turn, improve quality of care and outcomes for West Virginians with Alzheimer's and their families.

### **Recommendation 3.1**

**Foster a multi-pronged approach to research into the causes, diagnosis, treatment, care and cure of Alzheimer's disease.**

#### **Rationale:**

Research of all kinds, including basic science, translational, and behavioral, is needed to confront the challenges of Alzheimer's in West Virginia. A sustained, long-term commitment of resources is crucial to executing this effort.

Current drug treatments only slow the symptoms and are modestly effective. For 95 percent of individuals with Alzheimer's, there is no known cause other than advancing age. The remaining 5 percent have a familial form of the disease. Although some progress is being made in diagnosis, the disease cannot be confirmed until autopsy. Thus, the need persists for basic research into the causes of Alzheimer's, its detection, and potential cures.

Research also is needed on how to translate basic science Alzheimer research into appropriate clinical interventions, as well as explore how to improve care outcomes for people with Alzheimer's. Practitioners meet and treat the person with Alzheimer's, and during this process, an opportunity exists to validate and document the person's status using observation, clinical data (including medications), and valid and reliable instruments, including the Alzheimer's Disease Related Quality of Life (ADRQL™), Health Utilities Index (HUI®) Mark 3, Mini-Mental® Status Exam (MMSE), Neuropsychiatric Inventory (NI), and the Alzheimer's Disease Cooperative Study Activities of Daily Living Scale (ADCS-ADL).

As the state continues to move forward, further developing Alzheimer's focused research will require building partnerships, providing incentives for individuals to conduct research, attracting researchers, and funding to support capacity building. Implementing this inter-professional, multi-dimensional approach to Alzheimer research will help improve physical, social, emotional and cognitive quality of life for people with Alzheimer's; and hopefully, will lead to discovering how to most effectively detect, treat, and cure this disease.

**Responsible entities:** West Virginia Legislature, Bureau for Public Health, higher education institutions, and private and nonprofit research organizations

**Costs to the state:** High. Approximately \$1 million annually in grant funding for all types of research related to Alzheimer's.

**Timeline:** [MID TERM] As research takes time to develop, carry out, and disseminate, it must begin as soon as funding can be secured.

### **Recommendation 3.2**

#### **Support the West Virginia Alzheimer's Disease Registry to improve the collection of actual Alzheimer incidence information.**

##### **Rationale:**

The incidence of Alzheimer's in the aging population is increasing at an alarming rate both nationwide and in West Virginia. With many people not entering the medical system until very late in the disease process and often presenting with other complicating problems like diabetes or heart disease that are often easier to diagnose, reported estimates of people with Alzheimer's actually may represent just the "tip of the iceberg."

The West Virginia Alzheimer's Disease Registry is a state-mandated, population-based registry of patients with Alzheimer's. The Registry is a password-protected, encrypted database requiring annual software costs, as well as personnel, to enter, manage and analyze the data.

Registry data will populate statistical summaries of demographic, diagnostic and treatment information that will be used to advise physicians, patients, caregivers and policymakers at local and state levels about the medical, social and economic impact of Alzheimer's in West Virginia. Collaterally, it is anticipated that the collection of this data will improve the diagnosis, treatment and care of patients with Alzheimer's, and educate policymakers about the size of the problem and necessity of state funding for care and support.

The Legislature created the Registry in 2006, and it first received funding in 2009. Active operation of the Registry began in 2010, and to date, it has experienced only modest success in collecting data primarily due to lack of awareness. Physicians are required to report all cases of Alzheimer's. This reporting requirement meets the HIPAA exception as a "public health authority" activity. The details of data to be collected and procedures for their collection are further outlined in state procedural rules.

Despite the statutory and regulatory provisions allowing for enforcement of reporting requirements, stakeholders agree that a voluntary, outreach and information-driven approach is the most effective way to increase the number of physicians participating in the Registry. Continuing Medical Education presentations are a key method to reach physicians with information about the Registry's reporting requirements. Incentives also may help in increasing the number of physicians collecting and reporting patient information to the Registry. Education about the existence, purpose and value of the Registry directed toward people with Alzheimer's and their families also may empower people with Alzheimer's and their families to encourage their physicians to report.

With the uncompensated costs of providing care for patients with Alzheimer's approaching \$1.5 billion annually in West Virginia, reporting to the Registry is a relatively low-cost tool. When paired with outreach to physicians, patients and families about the diagnosis and treatment of Alzheimer's, the Registry can assist in attacking the encumbrance of Alzheimer's in West Virginia.

**Responsible entities:** West Virginia Legislature, West Virginia University, Blanchette Rockefeller Neurosciences Institute, and state medical societies

**Costs to the state:** High. Approximately \$200,000 annually to support outreach and education activities surrounding the Registry.

**Timeline:** [SHORT TERM] Support for training physicians about diagnosis, treatment and patient entry into the Registry should occur with two years of the adoption of the Alzheimer's State Plan.

### **Recommendation 3.3**

**Require that quality of care research be conducted on all state-funded services that target people with Alzheimer's and their caregivers.**

#### **Rationale:**

Research about Alzheimer's is aptly described as follows, "Two increasingly important outcomes in Alzheimer's disease research, quality of life and health utilities have been neglected entirely." (Miller, Rosenheck and Schneider, 2010, p. 348, Current Alzheimer Research)

The term "health-related quality of life" intentionally serves as an umbrella for describing the state of practice, treatment and research with respect to Alzheimer's. It includes the dimensions of cognitive, social, emotional and physical well-being. West Virginia practitioners are like their colleagues in other states in their ready acknowledgement of the challenge of developing a multi-dimensional plan for improving the organization and delivery of care for persons with Alzheimer's.

An important element of West Virginia's approach was the establishment of the statewide Alzheimer's Disease Registry; however, at this point, the Registry contains limited data on Alzheimer's and does not address services or quality of services. Many of the data elements that should be included in a multi-dimensional approach are not collected.

A second key element was the organization of knowledgeable resources to develop the Make A Plan for Alzheimer's initiative. As the state implements new state-funded Alzheimer services and evaluates any existing state-supported services, it should mandate that outcomes-based research occur on the quality of the care provided as part of the conditions for receiving state funding. This research could be conducted by state agencies themselves, academic and private research centers, or nonprofit entities.

**Responsible entities:** West Virginia Legislature, Bureau for Medical Services, Bureau for Public Health, Bureau of Senior Services, higher education institutions, and private and nonprofit research entities

**Costs to the state:** High. Approximately \$500,000 annually to conduct quality of care research.

**Timeline:** [SHORT TERM] As research takes time to develop, carry out, and disseminate, it must begin as soon as funding can be secured.

### **Recommendation 3.4**

**Conduct an evidence-based review of transitions of care models for people with Alzheimer's disease, and then, pilot these best practice approaches in West Virginia.**

**Rationale:**

Individuals with Alzheimer's are particularly at risk in times of transition. Because of inadequate funding sources and a variety of approaches to transitions of care, unnecessary delays and poor outcomes often occur for individuals with Alzheimer's when leaving hospitals and other institutional settings to move to home and community-based care or from home to a long-term care setting.

Transitions of care models encompass all avenues of care: hospital, long-term/short-term living and rehabilitation facilities and home and community-based programs and services. West Virginia needs to conduct research to determine the best models for our state. This research could be conducted by an academic research group with assistance from other organizations with Alzheimer expertise. Once several successful models with applicability to West Virginia are identified, these models should be piloted in several communities to test their capability to assist in smoothing transitions of care.

**Responsible entities:** West Virginia Legislature, Bureau of Senior Services, higher education institutions, Office of Health Facility Licensure and Certification, and private and nonprofit research organizations

**Costs to the state:** Moderate. Approximately \$40,000 to fund the initial study, with subsequent costs for funding pilots. Grant funding connected with the Affordable Care Act may be available to fund pilots.

**Timeline:** [SHORT TERM] Work on the evidence-based review can begin as soon as funding is secured. Once the evidence-based review is conducted, stakeholders would seek funding for pilot projects.





### **Recommendation 3.5**

**Maximize use of the Behavioral Risk Factor Surveillance System survey to collect data on the prevalence and impact of Alzheimer’s disease on people with the disease and their caregivers.**

**Rationale:**

The West Virginia Health Statistics Center, located in the Bureau for Public Health, receives funding from the federal Centers for Disease Control and Prevention (CDC) to conduct the annual Behavioral Risk Factor Surveillance System (BRFSS) survey. Since 1984, West Virginia has participated in this nationwide program, which collects health conditions and risk behavior data through random digit dialing telephone interviews.

Each year, the state works with CDC to assemble the questions that will be asked as part of the BRFSS. These questions are arranged topically in “modules.” In recent years, the CDC has developed modules on cognitive impairment and caregiving. For 2011 and 2012, the West Virginia BRFSS includes the cognitive impairment module, and in 2012, it also will include the caregiver module.

These survey results will illuminate the epidemiology of Alzheimer’s and caregiver burden in the state, which in turn will help West Virginia researchers learn more about the disease and determine how to most efficiently target services.

The national Alzheimer’s Association provided a grant that underwrote the addition of these questions to the BRFSS in 2011 and 2012. In future years, the state would like to continue to include these questions at least every three years, but in order to do so, a funding source must be identified.

**Responsible entities:** West Virginia Legislature, Bureau for Public Health, Health Statistics Center, and nonprofit and private organizations and foundations

**Costs to the state:** Moderate. \$15,000 to \$20,000 annually to conduct both modules.

**Timeline:** [MID TERM] Funds have been secured to include both the cognitive impairment and caregiver modules in the 2012 BRFSS. Additional funding is needed to ensure this data collection continues to occur at least triennially.

### **Recommendation 3.6**

**Explore the creation of an independent Alzheimer's disease-focused social indicator survey.**

**Rationale:**

This specialized survey would collect information not already gathered by the Behavioral Risk Factor Surveillance System (BRFSS) survey or the West Virginia Alzheimer's Disease Registry. It would include questions about lifestyles, illness, insurance access, medications, living conditions, environmental exposures, access to transportation, and similar questions in order to collect critical information to improve the state's overall understanding of the impact of Alzheimer's.

In the 1990's, the West Virginia University Department of Sociology and its Survey Research Center successfully used this model to conduct the West Virginia Social Indicators survey of West Virginia households with a protocol similar to, but slightly less rigorous than the BRFSS.

The creation, execution and analysis of this type of survey could be supported through a variety of funding streams, such as a mixture of state, nonprofit and private organizations and foundations. The survey would be conducted every other year.

**Responsible entities:** Bureau for Behavioral Health and Health Facilities, Bureau for Medical Services, Bureau for Public Health, higher education institutions, and nonprofit and private organizations and foundations

**Costs to the state:** High. Approximately \$200,000, but costs may vary slightly depending on what entities fund the survey.

**Timeline:** [SHORT TERM] Activities could begin as soon as funding is secured.

## GLOSSARY

*The Care Systems Working Group created this glossary and its purpose is to describe the most frequently used care systems and direct services for people with Alzheimer's and their family and lay caregivers. These definitions are intended to provide a general sense of meaning and in some cases may not be comprehensive or reflect West Virginia statutory or regulatory definitions.*

**ACUTE CARE SYSTEMS** are hospitals (general medical/surgical, psychiatric, and inpatient rehabilitation facilities) and ambulatory care facilities, such as doctors' offices and urgent care facilities, which provide emergency and general medical services specifically for the purpose of caring for acute disorders rather than providing long-term residential care that addresses chronic illnesses.

**ADULT DAY CARE** is a community-based, group program designed to meet the need of older adults who cannot be left alone due to a cognitive or physical impairment. The program can be used for respite or as a long-term care service. Programs vary in services, but common offerings including: recreation, nutrition, socialization, respite, medical services, and healthcare services.

**ALZHEIMER'S ASSOCIATION, WEST VIRGINIA CHAPTER** is a nonprofit, donor supported agency dedicated to providing supportive services and education to people with Alzheimer's, their families, and their caregivers. The West Virginia Chapter serves all of West Virginia and six counties in Ohio. Services include a 24/7 Helpline offering information about available services or emotional support, support groups, and community and professional education.

**ASSISTED LIVING FACILITIES** are a type of long-term care facility available for four or more residents that provide personal assistance or supervision to residents who may require nursing care at a level that is less intense than care provided at nursing facilities. Assisted living facilities provide a variety of services due to the fact that no nationally recognized definition of assisted living exists. Facilities often provide personal supervision and/or assistance with activities of daily living (ADLs), monitoring of resident activities to ensure health and safety needs are met, coordination of services by outside providers, administration and supervision of medications, and personal care provided by trained staff.

**COUNTY AGING PROVIDERS** (senior centers) are nonprofit service agencies designed to meet the various needs of older adults in their communities and assist them in aging in place to the fullest extent possible, while improving their quality of life and preserving their dignity. They provide a physical location and professional staff to provide direct care and to assist older adults, their families, and caregivers in locating and accessing resources. Centers receive both federal and state funding to provide home and community-based services. Most services provided are not Alzheimer's disease specific.

FAIR (Family Alzheimer's In-Home Respite) is a state-funded program administered by the Bureau of Senior Services. It provides respite to family caregivers by providing direct care services to the person with Alzheimer's through one-on-one attention and individualized activities. Clients receive up to 16 hours of service per week based on the availability of hours and direct care workers. This program is fee-for-service with a sliding-fee scale based on the income of the person with Alzheimer's disease.

HOME and COMMUNITY-BASED CARE SYSTEMS are services designed to provide care for individuals with a variety of needs in their homes and communities. They include Medicaid Waiver and Personal Care; Adult Day Care; Lighthouse; Family Alzheimer In-Home Respite (FAIR); nutrition programs; support groups; and, transportation services. Support services are offered by organizations like county aging providers and the Alzheimer's Association. Many of these services are defined in more detail in this glossary.

HOSPICE provides medical and emotional care through a centralized system of palliative and supportive programs to terminally ill patients and their family members. Services are provided through an interdisciplinary team of professionals and volunteers that specialize in both home and inpatient settings.

LIGHTHOUSE is a direct service program funded by the state and administered by the Bureau of Senior Services. It provides support to seniors through personal care, mobility, nutrition, and/or environment. Seniors can receive up to 60 hours of service per month, based on need as determined by a nurse's assessment and availability of service workers (also known as caregivers or homemakers). Lighthouse is a fee-for-service program with a sliding-fee scale based on the participant's income. This program is not Alzheimer's specific.

LONG-TERM CARE FACILITIES are a type of residential care facility that include nursing facilities (also defined) and assisted living facilities (also defined).

MEDICAID PERSONAL CARE is an in-home service provided to people who meet medical and financial eligibility guidelines. Medical assessments are conducted by physicians and a participant's assets cannot exceed \$2,000, with income less than \$674 per month. Assistance includes personal hygiene, dressing, feeding, nutrition, environmental support, and health related tasks. This program is not Alzheimer's disease specific.

MEDICAID WAIVER (Aged and Disabled) program provides services to people 18 years of age and older who meet medical and financial eligibility guidelines. Medical eligibility is based on functional assessment conducted by a physician, and financial eligibility is determined by the Department of Health and Human Resources. Assets cannot exceed \$2,000 and income can be no more than \$2,022 per month. This program is not Alzheimer's disease specific.

**NURSING FACILITIES** are a type of long-term care facility designed to provide skilled care for people who are unable to care for themselves. Most facilities meet criteria for licensure established by sections of the Social Security Act that determine the basis for Medicaid and Medicare reimbursement for care.

**TRANSITION OF CARE** refers to the set of actions that ensure the coordination and continuity of healthcare services when a patient moves from one setting of care to another for the express purpose of addressing the patient's healthcare needs; this movement can be within the same facility or from one facility to another.

## REFERENCES

- Alzheimer's Association. 2011 Alzheimer's Disease Facts and Figures. Available at: [http://www.alz.org/downloads/Facts\\_Figures\\_2011.pdf](http://www.alz.org/downloads/Facts_Figures_2011.pdf).
- Alzheimer's Association. 2010 Alzheimer's Disease Facts and Figures. Available at: [http://www.alz.org/documents\\_custom/report\\_alzfactsfigures2010.pdf](http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf).
- Bass D, Clark P, Looman W, McCarthy C, Eckert, S. David M. Bass. The Cleveland Alzheimer's Managed Care Demonstration: Outcomes After 12 Months of Implementation. *The Gerontologist*. 2003; 43(1): 73-85.
- Brod M, Stewart A L, Sands L. Conceptualization and Measurement of Quality of Life in Dementia: The Dementia Quality of Life Instrument (DQoL). *The Gerontologist*. 1999; 39(1): 25-35.
- LeadingAge. Adult Day Service/Adult Day Health: Financial Viability and Scope of Services Provided Under Medicaid Waivers. February 2011. Available at: <http://www.leadingage.org/adultday.aspx>.
- Logsdon R G, McCurry S M, Teri L. Evidence-Based Interventions to Improve Quality of Life for Individuals with Dementia. *Alzheimer's Care Today*. 2007; 8(4):309-318.
- Miller EA, Rosenheck RA, and Schneider LS. Assessing the Relationship between Health Utilities, Quality of Life, and Health Care Costs in Alzheimer's Disease: The CATIE-AD Study. *Current Alzheimer Research*. 2010; (7): 348-357.
- Penna Della R D, Heumann K S, Gade G, Venohr I. Evidence-Based Clinical Vignettes from the Care Management Institute: Alzheimer's Disease and Dementia. *The Permanente Journal*. 2002; 6(2):1-11.
- West Virginia Alzheimer's/Dementia Special Care Unit Training. W.Va. Code R. §64-85-4.
- West Virginia Alzheimer's Disease Registry. W. Va. Code § 16-5R-7; W.Va. Code R. § 64-94.
- West Virginia Assisted Living Dementia Training. W.Va. Code R. §64-14-5.
- West Virginia Health Care Authority. 2010 Annual Report. Available at: <http://www.hcawv.org/DataAndPublic/AnnRpt/annualRpt10.pdf>.
- West Virginia Nursing Home Dementia Training. W.Va. Code R. §64-13-11.
- West Virginia Long-Term Care Partnership Program. W.Va. Code §9-4E-1.

West Virginia Partnership for Elder Living. Behavior-Related Exits from Long-Term Care by People with Alzheimer's Disease. December 2010. Available at:  
<http://www.wvpel.org/library.htm>.



## APPENDIX

### SENATE CONCURRENT RESOLUTION NO. 38

(By Senators Stollings, Wells, Foster, Unger, Jenkins, McCabe, Miller, Laird, Prezioso, Williams, Klempa, Kessler (Acting President) and D. Facemire)

Requesting the Joint Committee on Government and Finance to study the needs, challenges and issues facing West Virginians with Alzheimer's disease and their families for the purpose of making recommendations on how the State of West Virginia can better assist them in getting the care, research, support and treatment they deserve.

Whereas, According to the national Alzheimer's Association, there are currently 5.3 million Americans and forty-eight thousand West Virginians with Alzheimer's disease; and

Whereas, The greatest risk factor for developing Alzheimer's is age and according to the US Census Bureau in 2008 West Virginia had the third highest median age in the nation; and

Whereas, Alzheimer's is the sixth leading cause of death in this country, yet according to the West Virginia Bureau for Public Health Statistics it is the fifth leading cause of death in West Virginia; and

Whereas, West Virginia's rate for mortality from dementia is eleven percent higher than the national average; and

Whereas, Alzheimer's is increasingly viewed as having a vascular basis and subject to the same risk factors as stroke and cardiovascular illness such as smoking, high cholesterol, obesity and diabetes. According to the Behavioral Risk Factor Surveillance System, in 2008 West Virginia ranked first in the nation in the prevalence of smoking and diabetes; and

Whereas, Between 1998 and 2007 the rate of hospital discharges in West Virginia with dementia as a principle diagnosis increased twenty-nine percent; and

Whereas, The Alzheimer's Association estimates there are more than one hundred thousand family members caring for a loved one with Alzheimer's in West Virginia; and

Whereas, Biomedical research is an investment in the future economic diversity of our state; and

Whereas, West Virginia is home to a world-class Research Institute dedicated to finding a cure for Alzheimer's disease; and

Whereas, One proven way to collect information about the number of people in West Virginia with Alzheimer's disease and related dementia is through a population-based disease registry, West Virginia Alzheimer's Disease Registry; and

Whereas, West Virginia physicians should receive the best evidence-based continuing medical education related to screening, diagnosing and treating patients with Alzheimer's disease and related dementia; and

Whereas, The Alzheimer's Association is currently working with stakeholders throughout West Virginia to develop a long-term plan to address Alzheimer's disease in West Virginia; and

Whereas, The State of West Virginia is committed to developing a long-term plan to address Alzheimer's disease and in enhancing services and support to provide assistance to individuals with Alzheimer's disease and their families in getting the care, research, support and treatment they need; therefore, be it

*Resolved by the Legislature of West Virginia:*

That the Joint Committee on Government and Finance is hereby requested to study the needs, challenges and issues facing West Virginians with Alzheimer's disease and their families for the purpose of making recommendations on how the State of West Virginia can better assist them in getting the care, research, support and treatment they deserve; and, be it

*Further Resolved*, That the Joint Committee on Government and Finance report to the Legislature, on the first day of the regular session, 2012, on its findings, conclusions and

recommendations together with drafts of any legislation to effectuate its recommendations; and,  
be it

*Further Resolved*, That the expenses necessary to conduct this study, to prepare a report, and to draft necessary legislation be paid from legislative appropriations to the Joint Committee on Government and Finance.