THE 2009 REPORT OF THE VIRGINIA ALZHEIMER'S DISEASE AND RELATED DISORDERS COMMISSION: RECOMMENDATIONS OF THE COMMITTEE

The Virginia Commission on Alzheimer's Disease and Related Disorders advises the Commonwealth on the care of persons with Alzheimer's disease, dementia due to other causes, and how to assist caregivers of such persons. This is an enormous constituency, which represents one of the largest consumers of state and community resources (see the sidebar on the right).

Acting in its advisory capacity, the Commission recommends actions to enhance Virginia's ability to effectively and efficiently serve the relevant constituencies. Specific short and long term recommendations are included below.

A) SHORT TERM RECOMMENDATION: FOCUS ON RESPITE CARE

The Commission recommends enhancing availability and utilization of respite care resources.

BACKGROUND

Respite care, as defined by this Commission, is any service or set of services that allows a caregiver of a demented individual to temporarily escape from the caregiver[1] role.

An important and frequently overlooked part of the caregiving process is taking care of the caretaker. Families, not social service agencies, nursing homes, or government programs, are the mainstay underpinning long-term care for older persons in the United States. More than 22.4 million persons are informal caregivers–providing unpaid help to older persons who live in the community and have at least one limitation on their activities of daily living. These caregivers include spouses, adult children, and other relatives and friends.

Respite care gives caregivers a much needed break. The dictionary defines "respite" as "a delay or cessation for a time, especially of anything distressing or trying, an interval of relief." The term "respite care," however—within a professional acceptance—is a multi-agency response to the needs of such caregivers and typically refers to a range of interventions from sitting services, day-care services, to short-term residential and in-patient care.

Respite offers the caregiver time away from the stresses and strains of providing care and managing work, their household and family life. Most caregivers are employed, and nearly one in five provides more than 40 hours of care per week. Respite care also allows the care recipient a break from the caregiver and exposes them to different people with varied skills.

Depending on the need and situation, respite care services can include adult day care and homecare services as well as overnight stays in a facility. They may be provided for a few hours, days, overnight, a week, or weekend.

Statistics published in the Alzheimer's Association fact sheet at www.alz.org:

- An estimated 5.1 million Americans have Alzheimer's disease. The number of Americans with Alzheimer's has more than doubled since 1980.
- **Between 2000 and 2010, Virginia will experience a 30% growth in the number of people 65+ with Alzheimer's disease.**
- **In 2005, Virginia had almost 250,000 caregivers with an equivalent of 215,563,228 hours of unpaid care per that year valued at over $2.1 billion.**
- The number of Americans with Alzheimer's disease will continue to grow – by 2050 the number of individuals with Alzheimer's could range from 11.3 million to 16 million.
- National direct and indirect annual costs of caring for individuals with Alzheimer's disease are at least $100 billion, according to estimates used by the Alzheimer's Association and the National Institute on Aging.
- Alzheimer's disease costs American business $61 billion a year, according to a report commissioned by the Alzheimer's Association. Of that figure, $24.6 billion covers Alzheimer health care and $36.5 billion covers costs related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism and worker replacement.
- More than 7 out of 10 people with Alzheimer's disease live at home, where almost 75 percent of their care is provided by family and friends. The remainder is "paid' care costing an average of $19,000 per year. Families pay almost all of that out of pocket.
- Half of all nursing home residents have Alzheimer's disease or a related disorder.
- The average cost for nursing home care is $42,000 per year but can exceed $70,000 per year in some areas of the country.
- The average lifetime cost of care for an individual with Alzheimer's is $174,000.

[1] *The term 'family caregiver' means an adult family member or another individual who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction – Older Americans Act of 1965 as amended in 2006, Sec 203.*

Adult day care is available through:

- Social day care (providing social activities, meals, recreation, and limited health-related services).
- Adult health day care (offering more intensive health, therapeutic, and social services for individuals with severe medical problems). Adult day care is useful for caregivers who cannot stay home all day to provide care, supervision, and companionship.

In-home respite care combines health care and support services to help people with disabilities continue living at home as well as possible. Two types of home care are available:

- Home health care services provide medical care such as medication assistance, nursing services, and physical therapy.
- Non-medical home care services include personal care, companionship, housekeeping, cooking, and other household activities.

Institutional respite care in nursing homes, assistive living centers, and occasionally hospitals, provide respite care for individuals with disabilities who need to be away from home overnight or for several days. They can handle people in need of more care.

RECOMMENDATIONS

The Commission recommends that the Governor and the 2010 session of the General Assembly adopt the recommendation of the Joint Commission on Health Care to provide $200,000 in additional General Funds during each year of the biennium for the ***Respite Care Initiative*** *grant (administered by the Virginia Department for the Aging) which enables a caregiver of an individual with dementia to have a temporary rest from the caregiver role. At present, there are 207 families on the waiting list for this service. The requested funding would allow approximately 132 additional families to benefit from the Respite Care Initiative. The Commission recognizes the fiscal realities currently facing the Commonwealth. Nonetheless, the program for which we are advocating immediately impacts vulnerable persons and their families.*

The Commission also recommends that the "sunset clause" found in the Commission's legislation (§2.2-720 of the Code of Virginia) be extended until July 1, 2014.

The Commonwealth stands to benefit from enhanced availability and utilization of respite resources for the following reasons:

1. **Respite care resources allow caregivers to continue within the taxable workforce, which increases the tax base and in turn helps pay for increased respite program investment.**

   Caregiving has a substantial impact on business. Absenteeism, replacing employees who quit in order to provide care and other caregiving-related activities can have serious financial consequences to employers.

   Most caregivers are employed. Based on a 2003 AARP study, among baby boomer caregivers (aged 50-64 years old), an estimated 60% are working full or part-time. Using data from the 1998 National Survey of Families and Households (NSFH), working caregivers often suffer many work-related difficulties due to their dual caregiving roles. Among working caregivers caring for a family or friend aged 65+, two-thirds report having to rearrange their work schedule, decrease their hours or take an unpaid leave in order to meet their caregiving responsibilities. Difficulties due to work and caregiving are even higher among those caring for someone with dementia.

   A 1997 MetLife Mature Market Institute study reported U.S. businesses were experiencing a combined loss of $11.4 billion per year due to lost productivity created by employees providing

Caregiving Fact: The average caregiver is age 46, female, married and working outside the home earning an annual income of $35,000.

Caregiving statistics (based on the Family Caregiver Alliance reports www.caregiver.org):

- **34 million adults** (16% of population) provide care to adults 50+ years.
- **8.9 million caregivers** (20% of adult caregivers) care for someone **50+ years who have dementia**.
- **5.8 - 7 million** people (family, friends and neighbors) provide care to persons **65+** who need assistance with everyday activities
- Unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S. and are estimated to reach **37 million caregivers by 2050**, an increase of 85% from 2000.
- Cost of informal caregiving in terms of lost productivity to U.S. businesses is $11 to $29 billion annually.
- Caring for older persons with dementia (as opposed to caring for someone with a physical disorder) costs more than **$18 billion a year in additional time spent by family and friends.**
- One study of community-residing Alzheimer's disease care recipients found that on average **each care recipient receives $23,436 worth of informal care** from family and friends. In comparison, only $8,064 of professional home care services per year is used by care recipients.
- As a result of their caregiving, informal caregivers are estimated to each lose an average of $25,494 in Social Security benefits, an average of $67,202 in pension benefits and an average of $566,433 in wage wealth. Combined, the result is a loss of $659,129 over a lifetime.

care for their aging parents and relatives. Ten years later—based on a study commissioned by the Alzheimer's Association (www.alz.org)-- staggering costs of $36.7 billion are solely related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism and worker replacement.

By supplying the much needed respite care umbrella of options and services, caregivers may remain within the workforce pool for a longer period of time, and continue to increase the tax base.

2. Increasing investment in respite care can create jobs, and can therefore benefit local economies.

According to estimates developed by HHS's Office of the Assistant Secretary for Planning and Evaluation (ASPE), after 2010 the demand for direct care workers will increase as the baby boomers reach age 85 (beginning in 2030). ASPE estimates project the demand for direct care workers to grow to approximately 5.7-6.6 million workers in 2050, an increase in the current demand for workers of between 3.8 million and 4.6 million. This increase in demand will be occurring at a time when the supply of workers who have traditionally filled these jobs is expected to increase only slightly.

- What is the estimated economic value of informal caregiving? If the services provided by informal caregivers (i.e. family, friends, neighbors) had to be replaced with paid services, it would cost an estimated $257 billion (in 2000 dollars).
- At the estimated value of $257 billion nationally, informal caregiving greatly exceeds the costs associated with home health care ($32 billion) and nursing home care ($92 billion) combined.

By increasing investment in respite care, additional jobs can be created to benefit the local and regional economies and benefit persons with dementia and their caregivers.

3. Respite care can delay time to nursing home placement, which can reduce dependence on Medicaid subsidization of long term care and result in substantial savings to the Commonwealth.

Several studies published over the past decade indicate that people with moderate dementia have been able to defer institutionalization by nearly a year when their family members received caregiver support services, including counseling, information and ongoing support. Effective interventions for moderately and severely impaired patients become particularly valuable if they delay institutionalization. A 2003 HHS Report to Congress had shown that a one-month delay in placement would yield savings of $1,863 in formal services. At current rates of nursing home admissions, a one-month delay among Alzheimer's disease and dementia admissions could save as much as $1.12 billion annually.

4. Respite helps preserve both the mental and physical status of caregivers, which keeps them productive in their communities and in the workforce.

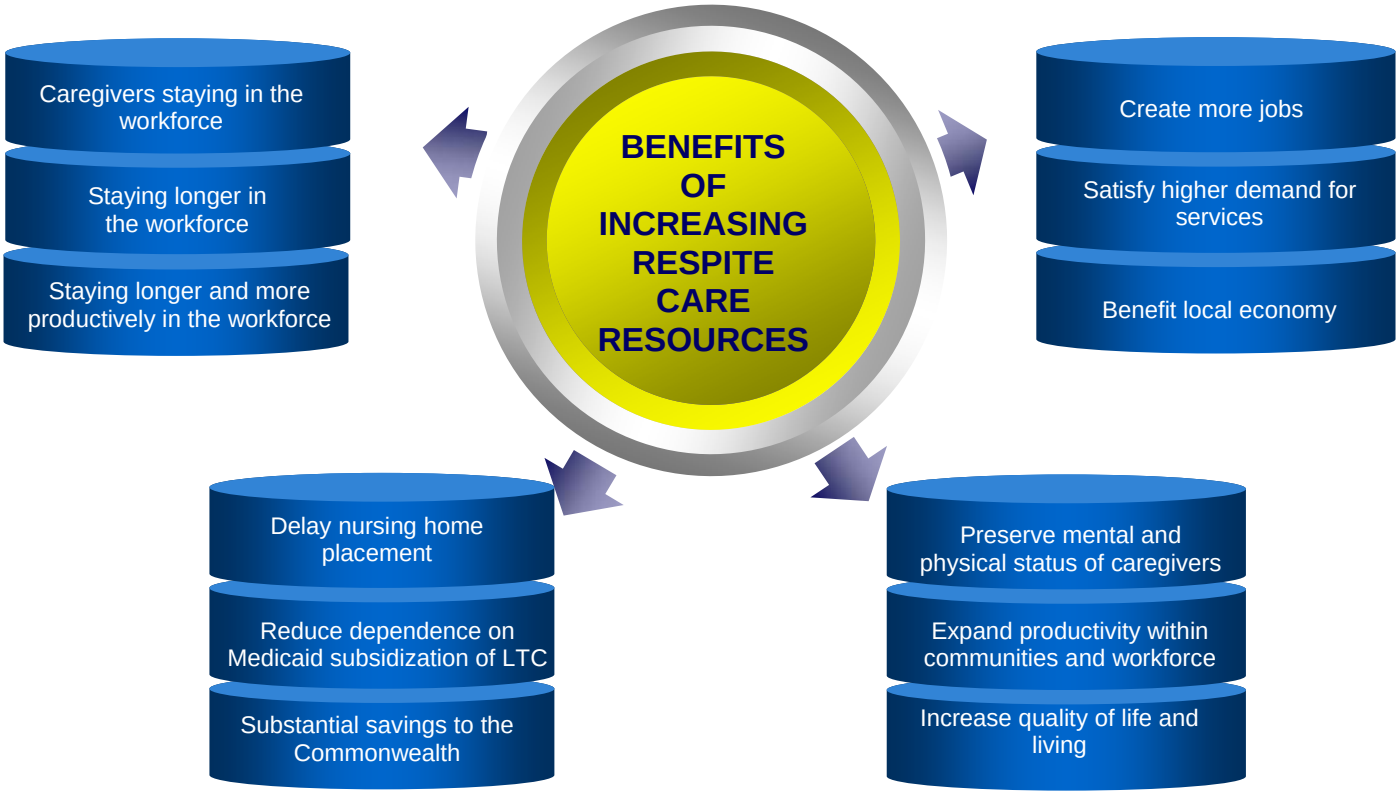
While experts have long known that caregiving can have deleterious mental health effects for caregivers, research shows that caregiving can have serious physical health consequences as well. A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than non-caregivers of the same age.

Psychological health appears to be the aspect of the family caregiver's life that is most affected by providing care. Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their non-caregiving peers (30% to 40% of dementia caregivers suffer from depression and emotional stress).

Caregiver interventions benefit both the caregiver and the care recipient. Use of caregiver support services, and in particular respite care, has been shown to have clinically significant outcomes in improving caregiver depression, anxiety, and anger. Specific caregiver interventions which appear most beneficial include those that work with both the caregiver and the care recipient, those that emphasize behavioral skills training, and those that are both multi-component and tailored to caregivers' specific needs.

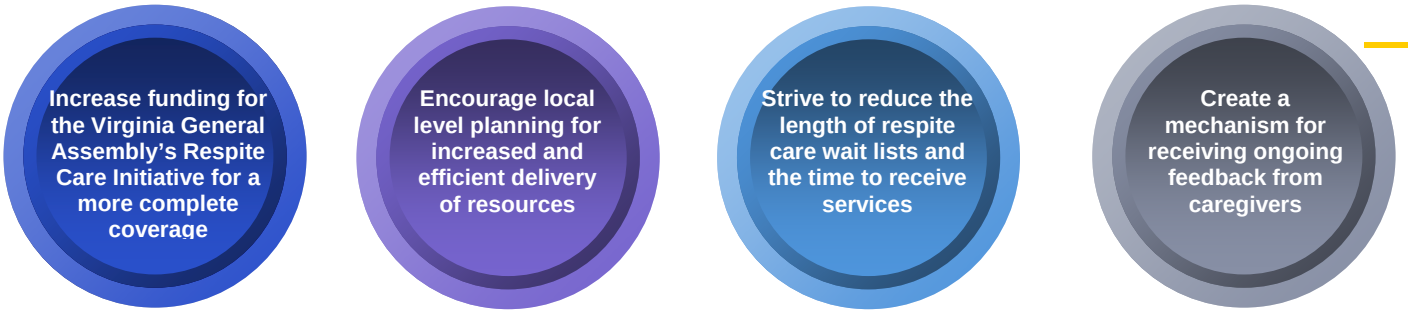
5. **Although the number of Alzheimer's patients in the Commonwealth has markedly increased in the past 20 years, the amount of funding by the Virginia General Assembly for its Respite Care Initiative has not increased proportionally.**

   The Virginia General Assembly created the Respite Care Initiative in the late 1980s. When the Virginia Department for the Aging took over the operation of this Initiative, the annual allocation was $350,000. In 2000, the Governor included an additional $250,000 for the Initiative in his budget (which passed) though due to revenue shortfalls and agency budget cuts in the early 2000s, the Initiative operates today with an annual budget of only $483,044.



The Commonwealth should enhance availability and utilization of respite care resources by:

1. **Increasing funding** for **the Virginia General Assembly's Respite Care Initiative** to achieve a more balanced and eventually complete statewide coverage (expand coverage to locales currently not served by the program) See recommendation above;
2. **Encouraging local level planning** for increased delivery of resources (local agencies will decide how to organize service improvements, by either providing services to more people, or else providing more services to those already participating in respite programs);
3. Striving to **reduce the length of respite care wait lists** and the time to receive services once services are applied for (a reduction in wait lists and wait times should be used as outcome measures);
4. Creating a **mechanism for receiving feedback from caregivers** on the state of respite care services (it is further recommended this mechanism be provided through the Virginia Alzheimer's Commission AlzPossible Initiative website).



B) LONG-TERM RECOMMENDATIONS: FOCUS ON VACAPI

The Commission's long-term recommendations are to enhance the effective and efficient utilization of dementia services and public dollars through support of the Virginia Alzheimer's Commission AlzPossible Initiative (VACAPI). This initiative represents the culmination of a multi-year effort by the Commission. With VACAPI, the Commission has successfully created an infrastructure to facilitate delivery of Alzheimer's disease-relevant services to targeted constituencies. The following VACAPI services are currently available throughout the Commonwealth:

- *The Education, Outreach, and Information Core* which has launched an **interactive forum and live webinar series** designed to address questions posed and issues faced by Virginia citizens with Alzheimer's disease, as well as their caregivers; and

- *The Administrative Core* which has successfully created and maintained **an official website** accessible to Virginia citizens wishing to learn more about the Commonwealth's commitment to those affected directly (patients) or indirectly (caregivers) by Alzheimer's disease.

RECOMMENDATION

To achieve the goal of enhancing an infrastructure to facilitate the delivery of Alzheimer's disease services, the Commission recommends the future investment of $400,000 for the VACAPI's organizational divisions or "cores," each of which address specific areas of need. This investment should be a component of future budgets once the Commonwealth's revenues increase and the overall economy improves.

FUTURE ACTION

The Virginia Commission on Alzheimer's Disease and Related Disorders is currently conducting public hearings across the Commonwealth seeking public input and comment as part of the development of a *State Plan for Dementia Care*. This plan will serve to advise policy makers, legislators, health and human services professionals, and citizens about best practices and strategies as we work to better serve individuals with dementias along with their family members, friends, and informal care providers. Once this plan has been developed, the Commission will approach the General Assembly to incorporate it into the Commonwealth's ongoing planning requirements.