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Alzheimer's Disease and Other Related Dementia State Plan

Senate Joint Resolution 43
Report to the Governor and General Assembly

2009

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Preface

In 1984, the Illinois General Assembly developed a plan to prepare for the predicted Alzheimer's disease and related disorders epidemic. Alzheimer's disease does not discriminate based upon age, race, marital status, country of origin, religion or sexual preference. It is a disease that leaves no survivors.

In 2003, a Legislative Task Force on Alzheimer's Disease studied the problem and submitted a number of recommendations to the General Assembly. The background section of that report concluded that Illinois must renew its commitment and develop a more aggressive state plan and ensure that the framework of programs and services established by the 84th General Assembly were functioning and capable of meeting the challenge of this serious public health crisis.

The Illinois Alzheimer's Disease State Plan, mandated by Senate Joint Resolution 43, is the result of collaborative efforts between Alzheimer's researchers, academia, physicians and other healthcare providers, the Alzheimer's Disease Assistance Centers, the Alzheimer's Association, various Illinois governmental units, concerned agencies, and citizens.

This multi-year plan is filled with recommendations, some of which can be implemented immediately and others, over time, to provide persons with Alzheimer's disease and related disorders, their families and their caregivers, a strategy to address this healthcare issue.

Although Alzheimer's disease is the primary dementia referred to throughout this document, it is the committee's belief that the recommendations are beneficial to a variety of medical conditions that also result in progressive dementias. Alzheimer Disease is the most common form of dementia, accounting for two-thirds of all dementias. The remaining one-third comprise a variety of other forms affecting a wider population, often at a younger age and requiring differing medical treatment strategies than typical Alzheimer's disease, and most of which remain untreatable, incurable and equally devastating to families. The recommended legislative and regulatory initiatives and changes in this report are equally important to those who are afflicted with the related dementias.

We respectfully submit this state plan to the Governor and the members of the Illinois General Assembly for consideration and action.

Members of the Alzheimer's Disease Advisory Committee
January 2009

Executive Summary

This 2009 Alzheimer's Disease and Other Related Dementia State Plan is comprised of a series of recommendations submitted by the Alzheimer Disease Advisory Committee. The plan's recommendations were created by Alzheimer's experts, Alzheimer's researchers, physicians and other health care providers, the Alzheimer's Disease Assistance Centers, the Alzheimer's Association, and other stakeholders.

The 2008 Alzheimer's disease facts and figures were compiled to reflect the magnitude of the Alzheimer's disease epidemic.

For purposes of readability, these recommendations are presented in a short summary of those recommendations deemed of greatest importance by the developers of the plan, followed by a more detailed explanation of each recommendation.

Alzheimer's Disease and Related Dementias Facts and Figures

Today, as many as 5.2 million Americans are living with Alzheimer's disease, the sixth leading cause of death in the country and the fifth leading cause of death for those older than age 65. Projections are that the disease will strike 10 million baby boomers, or one in every eight.

By 2010, there will be approximately 500,00 new cases of Alzheimer's disease each year in the United States; and by 2050, that number could reach 1 million each year. Young onset Alzheimer's rates (developed before age 65) are rising. Alzheimer's is not a disease that limits itself to age, race, marital status, country of origin, religion or sexual preference. It is poised to become the greatest health care crisis facing the United States in the next decade.

To put in to perspective the personal and economic impact of Alzheimer's disease and related dementias on persons with the disease, their families and caregivers, and the state and federal governments, statistics about Alzheimer's disease and related dementias are presented in this state plan. The Alzheimer's Disease Advisory Committee chose to use a single resource for the statistics for purposes of consistency. A much more extensive compilation of facts and figures than those in this state plan, published by the Alzheimer's Association in 2008¹, was chosen as this source.

Nearly 1 million people in Illinois are impacted by Alzheimer's disease or related dementias today. According to 2008 Facts and Figures, in 2007 there were 210,000 persons with Alzheimer's disease or related dementias living in Illinois. In Illinois, more than 347,000 caregivers provided nearly 300 million hours of unpaid care to persons with Alzheimer's at a value of more than \$3 billion. Seventy percent of people with Alzheimer's and other dementias live at home where friends and family take care of them; the disease not only touches the individual but entire families. In the United States the total value of this unpaid care was \$89 billion. The extent to which these costs would affect the state and federal government should these caregivers become unwilling or, more likely, unable to serve would be enormous.

While data² indicate that between 2000 and 2005 death rates have declined for most major diseases-- heart disease (-8.6 percent), breast cancer (-.8 percent), prostate cancer (-4.9 percent) and stroke (-14.4 percent) -- during that same period, Alzheimer's disease deaths continued to trend upward, increasing 45 percent. This disease leaves no survivors.

With appropriate resources, researchers believe they will be able to develop treatments to stop the increased percentage of deaths due to Alzheimer's disease or related dementias, actually begin to reduce those numbers and to improve the quality of life for persons with Alzheimer's, their families and their caregivers.

The states and the federal government should be preparing as thoroughly and responsibly for the increased number of persons with Alzheimer's disease and related dementias.

¹ Statistical Abstract of U.S. Data on Alzheimer's disease published by the Alzheimer's Association: 2008 Facts and Figures

² U.S. Centers for Disease Control and Prevention as cited in fn 1

Committee General Recommendations

While preparing this 2009 Alzheimer's Disease and Other Related Dementia State Plan, the committee found certain themes were consistent in two or more of the subcommittee reports. To avoid redundancy and to stress the importance of these issues, they are listed as "**Committee General Recommendations.**" These general recommendations comprise the heart of this state plan (Rationale for these recommendations begins on page 9). This state plan also includes recommendations from each subcommittee formed by the Alzheimer's Disease Advisory Committee.

Recommendation 1

Establish, adequate staffing levels and fund an Office on Alzheimer's Disease and related dementias within the Illinois Department of Public Health.

Build a central clearinghouse of widely and conveniently available Alzheimer's related information, including Alzheimer's/dementia resources, treatments, research, specialized providers, research centers, support and other services for all persons with Alzheimer's disease and related dementias, their families and their caregivers, researchers, paid providers of care and those who come into contact with a person with Alzheimer's disease or related dementias.

Recommendation 2

Establish, initiate and require basic, specialized and periodic education and training, as appropriate, for persons throughout the state whose responsibilities make it likely that they may come into contact with persons with Alzheimer's disease and related dementia.

Recommendation 3

Study and, where necessary, propose modifications to the Alzheimer's Disease Assistance Act (410 ILCS 5/) and the Alzheimer's Disease Research Act (410 ILCS 407) to review the composition of the Alzheimer's Disease Advisory Committee and to facilitate Alzheimer's planning, treatment, care and research.

Subcommittee Recommendations

The following recommendations were made by the subcommittees formed by the Alzheimer's Disease Advisory Committee as outlined in Senate Joint Resolution 43. (Rationale begins on page 11)

Alzheimer's Disease Assistance (ADA) Center Review Subcommittee Recommendations

- Increase the overall level of state funding for Alzheimer's disease research, care and treatment for ADA centers and other entities.
- Provide incentives to the ADA centers for the development and implementation of collaborative efforts between the ADA centers, other academic institutions and stakeholders.
- Extend the existence and advance the work of the ADA Center Review Subcommittee by continuing its operation after this state plan is submitted.
- Regularly analyze the current funding formulas for the ADA centers.

Geri-Psych Units Subcommittee Recommendations

- Convene a workgroup of physicians and other mental health and Alzheimer's specialists to determine the adequacy of geriatric-psychiatric hospitals, both by number and location, and to establish a consensus plan outlining parameters for the type and length of treatment that should be provided to persons with Alzheimer's disease and related dementias in hospital geriatric-psychiatric units. Determine and implement protocols for placement and release from geriatric-psychiatric hospitals.
- Establish protocols for community-based systems of care to meet the needs of persons with Alzheimer's disease and related dementias who exhibit behaviors requiring interventions.
- Expand opportunities and provide incentives for advanced education for primary healthcare providers who specialize in the treatment of persons with Alzheimer's disease or other dementias who require geriatric-psychiatric services.

Home and Community-Based Resources Subcommittee Recommendations

- Provide sufficient public funding and resources for adult day services for all persons with Alzheimer's disease and related dementias requiring these services are at rates that clients can reasonably pay.
- Provide physical, emotional and financial assistance to unpaid caregivers of persons with Alzheimer's disease and related dementias, including accessible, available and affordable day services, respite services, support services for caregivers and financial assistance considering the type and amount of services provided.
- Expand public funding, accessibility, availability and affordability of other home-and-community-based resources throughout the state for persons with Alzheimer's disease and related dementias of any age and at any stage of the disease, regardless of income level. Accessible and available means a sufficient number of resources and the means to access those resources (both financial and transportation).
- Equalize public benefits for all persons with Alzheimer's disease and related dementias whether funding is provided by the Illinois Division of Rehabilitation Services (for those

in the program before age 60 including persons with young onset Alzheimer's) and the Illinois Department on Aging, the Medicaid program, or some other source.

Population and Trends Subcommittee Recommendations

- Determine the most effective system (either the national Behavioral Risk Factor Surveillance System (BRFSS) system or a similar system) to collect data regarding prevalence, population trends, service needs and the impact of Alzheimer's disease and related dementias on persons with the disease, their families and their caregivers, and implement that system. Review the data collected to prioritize those in greatest need of program and services.
- Create incentives for caregivers to permit them to continue to provide services to persons with Alzheimer's disease or related dementias, such as necessary training, support and financial assistance, if needed, to allow these persons to remain in the most homelike setting for as long as possible.
- Work with Congress to increase Alzheimer's research funding and to eliminate barriers for persons with young onset Alzheimer's to receive federal benefits.

Public Safety and Law Enforcement Subcommittee Recommendations

- Implement a coordinated protocol for swift and appropriate action by law enforcement, the news media, and other entities upon a report of a missing endangered senior who is incapable of returning to the individual's residence without assistance. Most persons with Alzheimer's disease or related dementia will meet these criteria.
- Fund the distribution and monitoring of locator devices for eligible persons with Alzheimer's disease or related dementias.
- Increase the visibility and impact of local triads¹ to protect persons with Alzheimer's disease in each community.

Research Subcommittee Recommendations

- Develop strategies to attract, grow and track Alzheimer's research funding in Illinois through the Alzheimer's research centers, universities and colleges, not-for-profit organizations and other stakeholders.
- Develop strategies to protect the Alzheimer's Disease Research Fund.
- Review and, if necessary, restructure the Alzheimer's Disease Advisory Committee to make it a more pertinent part of Alzheimer's policymaking in the state and clearly outline these responsibilities in statute and develop rules that may extend its responsibilities.

Alzheimer's Special Care Units Subcommittee Recommendations

- Extend the applicability of the Alzheimer's Special Care Disclosure Act to entities providing care to persons with Alzheimer's disease and related dementias whether or not they "hold themselves out and providing Alzheimer's care in a distinct unit or center".
- Raise the standards of care for entities providing care and services to any persons with Alzheimer's disease or related dementias throughout the entity, including but, not limited to, entities without Special Care Units, as well as, in the Non-Special Care Unit sections of entities with Alzheimer's Special Care Units.
- Require Special Care Units and the Illinois Department of Public Health to provide consistent, publically available and accessible Special Care Unit information.

- Require improved accountability for care and treatment for persons living in special care units and all other entities caring for persons with Alzheimer’s disease and related dementias.
- Create a publically funded assisted living-level of care for persons with Alzheimer’s disease and related dementias who cannot pay privately for their care, such as a supportive living facility.

¹Triad is a partnership of three organizations - [law enforcement, senior citizens and community groups](#).

The sole purpose of Triad is to promote [senior safety](#) and to reduce the fear of crime that seniors often experience.

General Committee Recommendations - Rationale

Recommendation 1

Establish, adequately staff and fund an Office on Alzheimer's Disease and related dementias within the Illinois Department of Public Health to coordinate the state's policies, educate the public with respect to Alzheimer's disease, assemble, provide and maintain a clearinghouse of information, including funding resources on a 24/7 basis and pursue grants and other sources of funding.

Rationale

Services and support for persons with Alzheimer's disease and related dementias is divided among several state agencies, including the Illinois Department on Aging, Division of Rehabilitation Services; Illinois Department of Public Health; and, when necessary, the Illinois Department of Healthcare and Family Services. Persons seeking information and referrals should have a central point of contact. The Older Adult Services Act requires the creation of a central point of entry for those seeking aging services. Similarly, persons seeking information and other resources concerning Alzheimer's disease should have a centralized information source.

Currently, there is no one place to obtain this information. Like Chicago's 311 center, this office would serve as an information and referral source that identifies, creates and maintains a current data base that includes all available information such as research, trends, treatment options, information sources, and care and living options necessary for persons with Alzheimer's disease, their families and their caregivers and other stakeholders. The office should be culturally and geographically appropriate for individuals of any age and in any stage of the disease.

Recommendation 2

Establish and initiate training protocols for all persons who come into contact with persons with Alzheimer's disease and related dementias, including, but not limited to, first responders, state service personnel (i.e. Division of Motor Vehicles), and others in the community, as well as those in health care settings. Improve the skills and review and increase training for caregivers, medical specialists and generalists. Specific training in behavioral interventions for persons with dementia exhibiting challenging behaviors should be required for professionals and those in health care settings and encouraged in other settings.

Rationale

Persons with Alzheimer's disease or related dementias deserve appropriate, quality care and treatment, which requires the giver of that care or treatment to have specialized training and understanding of the conditions and behaviors of such individuals. Steps have been taken to require minimal training for some health care providers who are in direct contact with persons with Alzheimer's disease or related dementias (such as the 12 hour module in the CNA training curriculum), but even this minimal training is not required for all. Expenses to the state would be minimal as training programs already exist and additional curricula and training modules could be developed. For instance, the U.S. Department of Transportation has a standard curriculum available to states whose first responders would benefit from some training on dementia.

Dementia-specific training for individuals providing a gamut of services would benefit both the individual being trained and the person with Alzheimer's disease or related dementia. Individuals who should receive initial and periodic training include, but are not limited to: all hospital, assisted living, supportive living, nursing home, medical and dental clinics, medical agencies, local health departments and Illinois Department of Public Health and other state agency employees; emergency first responders, fire and police.

Currently, initial training for first responders and emergency call dispatchers is sporadic and it does not appear all entities require subsequent training. In order to recognize the symptoms of dementia and adequately deal with persons with Alzheimer's disease or related dementias, initial and subsequent training by first responders and emergency call dispatchers is essential. One hour of training is not adequate for an initial training program. It is recommended that both initial and continued training for a host of persons, both publically and privately employed.

Recommendation 3

Study and, where necessary, propose modifications to the Alzheimer's Disease Assistance Act (410 ILCS 5/) and the Alzheimer's Disease Research Act (410 ILCS 407) to facilitate Alzheimer's treatment, care and research.

Rationale

The Alzheimer's Disease Assistance Act and the Alzheimer's Disease Research Act have not been substantively amended for a number of years. A complete review of the act is needed to make these changes and any others required under the SJR43 state plan. The Alzheimer's Disease Advisory Committee, created in the Assistance Act, is one example. The Advisory Committee's makeup and responsibilities, as well as those of the Illinois Department of Public Health and the assistance centers, have not changed significantly since these acts became law in 1991. Composition of the Committee, including size, membership and diversity; policies; and all of the Committee's functions should be reviewed and updated.

There also are changes that could be considered with respect to the duties and responsibilities of the centers. For instance, they could be tasked to develop or seek additional sources of donations and contributions to increase funds available for research in the Alzheimer's Disease Research Fund.

Subcommittee Recommendations -Rationale

Alzheimer's Disease Assistance (ADA) Center Review

Introduction

This subcommittee was directed to review the Alzheimer's Disease Assistance Centers' annual (fiscal year) reports and provide approval and/or recommendations to the Alzheimer's Disease Advisory Committee meeting and to review the grant funding formula

Recommendation 1

Increase the overall level of state funding for Alzheimer's disease research, care and treatment for ADA centers and other entities.

- Develop strategies to raise the state funding levels for the ADA centers compared to states demographically similar to Illinois.
- Identify funding opportunities that may qualify for federal or private matches and to leverage additional dollars for the program.

Recommendation 2

Provide incentives to the ADA centers for the development and implementation of collaborative efforts between the centers, other academic institutions and other stakeholders.

- Reward the leadership efforts of the ADA centers.
- Charge the ADA centers with the responsibility to create strategic alliances between the ADA centers and other academic institutions throughout the state.
- Task the ADA centers to work with other entities to identify and engage additional stakeholders, including state chapters of the Alzheimer's Association, to participate in the development of these strategic alliances, and to assist the ADA centers to identify needs and opportunities for new initiatives.
- Create a system that rewards the ADA centers for the development and implementation of collaborative efforts between the ADA centers, other academic institutions and other stakeholders.
- Develop a joint report to be presented to the Committee each year that reports individual ADA center programs, but highlights the cooperative efforts of the ADA centers.

Recommendation 3

Extend the existence and advance the work of the ADA Center Review Subcommittee by continuing its operation after this state plan is submitted.

Recommendation 4

Regularly review the current funding formulas for the ADA centers.

Rationale

The collaborative efforts of the ADA Center Review Subcommittee have proven to be effective to bring together multiple stakeholders with different perspectives. The continuation of this subcommittee would allow this cooperative process to continue and to expand, benefitting persons with Alzheimer's disease, their families and their caregivers, the ADA centers, academic entities, and other stakeholders.

In 2003, the state provided \$3 million in grant funding to the ADA centers to conduct research to develop better treatments and disease prevention strategies. This funding was reduced to less than \$2 million in FY 09. Example of funding levels for states similar to Illinois for their ADA center programs include Florida at \$16.62 million last year, California at \$5.85 million last year, and Arizona at \$4 million last year. The committee and the Department should work with the General Assembly to raise the state funding levels for the ADA centers to those of states demographically similar to Illinois.

Much work has been done through the cooperative efforts of the members of the SJR 43 subcommittees. It is important that this progress continue, particularly with respect to the ADA centers. Additional work, time, and cooperation will benefit the ADA centers, and ultimately, persons with Alzheimer's disease and related dementias.

Geriatric-Psychiatric Subcommittee

Introduction

This subcommittee's responsibility was to identify the adequacy and appropriateness of geriatric-psychiatric units for persons with behavioral disorders associated with Alzheimer's and related dementias and existing services.

Recommendation 1

Convene a workgroup of physicians and other mental health and Alzheimer's specialists to determine the adequacy of geriatric-psychiatric hospitals, both by number and location, and to establish a consensus plan outlining parameters for the type and length of treatment that should be provided to persons with Alzheimer's disease and related dementias in hospital geriatric-psychiatric units. Determine and implement protocols for placement and release from geriatric-psychiatric hospitals.

Recommendation 2

Establish protocols for community-based systems of care to meet the needs of persons with Alzheimer's disease and related dementias who exhibit behaviors requiring interventions.

- Explore the concept of linking diagnostic codes at the hospital with reimbursement and level of training.
- Limit the use of hospital geriatric-psychiatric units to temporary stays for the most extreme cases only after all behavioral interventions are explored and, if appropriate, used.
- Identify the areas where community-based systems of care would be most beneficial to persons with Alzheimer's disease and related disorders with behavior issues beginning in those areas without access to any such services.
- Review the distribution of geriatric-psychiatric units. Permit the development of such units only in greatly underserved areas without such units and only if it can be demonstrated that the needs of the population cannot be met through a community-based system of care.

Recommendation 3

Expand opportunities and provide incentives for advanced education for primary health providers who specialize in the treatment of persons with Alzheimer's disease or other dementias who require geriatric-psychiatric services.

- Promote Alzheimer's research using incentives as necessary.
- Determine and develop the funding and other mechanisms to provide incentives to bring qualified health care providers into the community-based system of care throughout the state. These incentives may be both financial and non-financial, such as forgiveness of loans or loan repayment options, stipends, scholarships funded by the state and from other resources and relocation expenses.

Rationale

Common behaviors of persons with cognitive impairments (including Alzheimer's disease and related dementias) include aggression, threats (both verbal and physical), sexual inappropriateness, elopement, paranoia, delusions and hallucinations. In the most challenging

situations, a person with a cognitive impairment may be referred to a geriatric-psychiatric hospital for a short stay before being returned to their place of residence³. The current system for accessing behavioral care relies on the hospital emergency department as the access point for the geriatric-psychiatric unit for behavioral treatment. It is inadequate, inefficient and inappropriate.

The availability of hospitals and geriatric-psychiatric beds is very low, particularly outside Cook County. Training is not standardized and is not provided to staff in several of these hospitals with dementia units. Similarly, there are a limited number of health care professionals specializing in the needs of persons with geriatric psychological issues.

The current model will not be capable of meeting the future needs of persons with Alzheimer's disease and related dementias who exhibit advanced behavioral issues for a number of reasons, including lack of consensus about the best methods to treat persons with cognitive impairments that require intervention and a lack of health care professionals currently trained in dealing with the psychiatric needs of those persons with Alzheimer's disease exhibiting behaviors requiring interventions, causing a lack of training for all caregivers and other health care personnel.

Assuming that the current model could be improved, it may be necessary to design incentives to encourage changes be made to meet the future needs of persons with Alzheimer's disease and related dementias with behavioral issues requiring intervention.

³ An increasing number of persons with Alzheimer's disease and related dementias are younger than age 60, thereby making the term "geriatric-psychiatric" a misnomer.

Home and Community-Based Services Subcommittee

Introduction

This subcommittee studied home and community-based resources available in Illinois. These resources are absolutely critical to ensure persons with Alzheimer's disease and other related dementias can be adequately cared for in their homes as long as possible to meet their wishes and to control the cost of health care. It is clear that, even among those who meet the eligibility and economic standards for service, there are great disparities in available services throughout the state including economical, geographical and environmental. But home and community-based services should be made available across the state to those who are impoverished and those who can pay for services. The issues are the availability and accessibility of these services.

Recommendation 1

Provide sufficient public funding and resources for adult day services for all persons with Alzheimer's disease and related dementias and requiring these services at rates that clients can reasonably pay.

Recommendation 2

Provide physical, emotional and financial assistance to unpaid caregivers of persons with Alzheimer's disease and related dementias, including accessible, available and affordable day services, respite services, support services for caregivers and financial assistance considering the type and amount of services provided by currently unpaid caregivers.

Recommendation 3

Expand public funding, accessibility, availability and affordability of other home and community-based resources throughout the state for persons with Alzheimer's disease and related dementias of any age and at any stage of the disease, regardless of income level, such as available respite services. Accessible and available means a sufficient number of resources and the means to access those resources (both financial and transportation).

Recommendation 4

Equalize public benefits for all persons with Alzheimer's disease and related dementias whether funding is provided by the Illinois Department of Human Services Division of Rehabilitation Services (for those in the program before age 60 including persons with young onset Alzheimer's) and the Illinois Department on Aging, the Illinois Department of Healthcare and Family Services Medicaid program, or some other source.

- Seek any necessary waivers to:
 - Consolidate services to persons with any stage of Alzheimer's Disease and at any age that it develops, including young onset.
 - Allow a family member, including a spouse, to receive some form of financial incentives for their services and for the additional costs incurred in order to care for a person with Alzheimer's disease at home.
- Standardize the service package for every person with Alzheimer's disease, whether they are younger or older than age 60.
- Study the feasibility of merging the responsibilities of the Illinois departments on Aging, Public Health, and Healthcare and Human Services with respect to persons with

Alzheimer's disease and their caregivers recognizing that some of these departments may have a role in the grant and/or payment process.

Rationale

Home and community-based services are essential for a number of reasons:

- There are the type of services being requested.
- The federal government is encouraging states to focus on home and community care rather than in institutional care.
- Home and community-based care is more economical (in most cases) than institutional care at a time when state and federal budget dollars are strained.

To allow a person with Alzheimer Disease to reside in the community, with caregiver support, for as long as possible, services must be available and support must be provided for caregivers to allow them to continue to provide services as long as possible. Without caregiver assistance to provide relief for caregivers, both emotional and financial, the costs to the current system would multiply. Providing sufficient and accessible services like respite care and adult day services, is much more economical than other alternatives. Where these services do not exist, they must be encouraged and where services do exist, they must be accessible and affordable. Even if the state increased the rates paid to adult day providers, the savings to the state would be beneficial.

Illinois' home and community-based resources and policies differ substantially between state human service agencies. For example, a person with young onset Alzheimer's disease receives one set of benefits, including the ability to designate who will provide their care under the Illinois Department of Human Services, Division of Rehabilitation Services (DRS) program; once this person becomes age 65, they may stay with the DRS program, which is not designed to care for the elderly, or transition to the Illinois Department on Aging's programs, which may provide a completely different package of benefits as well as causing a change in caregivers.

Population, Trends and Needs Subcommittee

Introduction

This subcommittee studied information from numerous sources concerning Alzheimer's disease prevalence, the quality and quantity of state support for caregivers and persons with Alzheimer's disease and related dementias, including early onset and early stage, and state policies concerning persons with Alzheimer's disease or related dementias. For purposes of this report, "Alzheimer's disease or related dementia" must be diagnosed. Persons with "cognitive impairments" are not included in the research or results from this report.

Recommendation 1

Determine the most effective system (either the national Behavioral Risk Factor Surveillance System system or a similar system) to collect data regarding prevalence, population trends, service needs and the impact of Alzheimer's disease and related dementias on persons with the disease, their families and their caregivers, and implement that system. Review the data collected and apply it so that programs and services for persons with Alzheimer's disease and related dementias can be prioritized to target those areas of greatest need.

Use the collected and analyzed data to develop age appropriate programs and services statewide to meet the current and future needs of persons with Alzheimer's disease or related dementias and their caregivers, such as an expansion of adult day care and respite services and accessible and available transportation.

Recommendation 2

Create incentives for caregivers to permit them to continue to provide services to persons with Alzheimer's disease or related dementias, such as necessary training, support and financial assistance, if needed, to allow these persons to remain in the most homelike setting for as long as possible.

- Conduct a pilot program that allows spouses to be paid caregivers; analyze and expand this benefit.
- Explore the effect of granting income tax credits to caregivers.

Recommendation 3

Work with Congress to increase Alzheimer's disease research funding and to eliminate barriers for persons with young onset Alzheimer's disease to receive federal benefits. The state Legislature should pass resolutions to encourage Congress to eliminate the Medicare two-year waiting period and to increase funding for Alzheimer's disease research in the FY09 and subsequent federal budgets.

Rationale

Although there are prevalence estimates, the incidence of persons with Alzheimer's disease and related dementias and their caregivers has not been determined in Illinois. There is a need for a validated instrument to collect and analyze data at both the state and county levels. Examination of this data could provide an abundance of information concerning persons with Alzheimer's disease and related dementias and their caregivers. There are several methods to collect data in

Illinois. One such instrument is the survey already conducted by the Illinois Department of Public Health. This survey is known as the Behavioral Risk Factor Surveillance System. The cost to add questions to the survey is approximately \$3,000 each. Several other methodologies exist as well.

Through anecdotal evidence, it appears that the impact of Alzheimer's disease on caregivers is substantial. Further study is necessary to confirm these estimates. This information will assist the state to accurately assess the state's benefits through the efforts of these caregivers. Once this information is known, a series of incentives may be reasonable as an alternative to the costs of placing the person with Alzheimer's disease or dementia into a nursing home or similar facility,

There is not a mechanism in place to report the number of deaths attributed to Alzheimer's. A great deal of education is needed so that primary care providers can consistently and accurately record the primary and secondary causes of death on death certificates. Without better practices, the number of deaths of persons with Alzheimer's disease and related dementias is being undercounted.

Public Safety and Law Enforcement

Introduction

This subcommittee studied the state's and Illinois communities' capacity to address the public safety and law enforcement needs of persons with Alzheimer's disease and related dementias. Both the safety of the person with Alzheimer's disease or related dementias and the safety of members of the public were considered.

Recommendation 1

Request that all older drivers who seek drivers license renewal be tested with all three tests currently used to examine new drivers: the written exam, the driven exam and the vision screening.

Recommendation 2

Implement a coordinated protocol for swift and appropriate action by law enforcement, the news media, and other entities upon a report of a missing endangered senior who is incapable of returning to the individual's residence without assistance. Most persons with Alzheimer's disease or related dementia will meet these criteria.

Recommendation 3

Fund the distribution of locator devices for eligible persons with Alzheimer's disease or related dementias. The Illinois Department on Aging funds emergency home response devices for those who qualify, but these systems are inappropriate for the Alzheimer's population.

Recommendation 4

Increase the visibility and impact of local triads⁴ to protect persons with Alzheimer's disease in each community.

Rationale

Research exists to assert that driving ability decreases with age and/or declining cognitive ability. The subcommittee's full report documents a number of these studies. There is a difference of opinion as to whether age or cognitive ability requirements, or both, should be changed. There must be further study and comparisons between aging and cognitive abilities as the most legitimate predictor of vehicle safety. The addition of the written exam for older adults easily adds a cognitive dimension to the renewal process and will increase the likelihood that those who may have Alzheimer's disease are recognized. Older drivers in Illinois are already tested according to an age-determined schedule, so adding the written exam as a routine requirement is a logical yet reasonably low-cost method, to screen for drivers who may have Alzheimer's disease. This will strengthen the state's ability to assure that its drivers are driving safely. Additionally, motor vehicle service facility personnel should be trained not to assist any person completing any part of the driving test, including vision, sign identification, the written test and behind the wheel. To do so may allow an otherwise unqualified person to receive a license.

⁴ Triad is a partnership of three organizations - [law enforcement, senior citizens and community groups](#).

The sole purpose of Triad is to promote [senior safety](#) and to reduce the fear of crime that seniors often experience.

About 3 million Americans with Alzheimer's disease and related dementias go missing each year. If an elderly person is not found within 24 hours, there is a 50 percent chance that he will suffer serious injury or die. Several years ago, Illinois passed legislation⁵ adding "missing endangered seniors" to the list of individuals who require the Illinois State Police to initiate immediate action through the statewide Law Enforcement Agencies Data System (LEADS). With respect to missing endangered seniors, however, the law does not extend beyond notification to law enforcement entities. An effective statewide emergency alert program must be established to aid in the identification and recovery of missing endangered adults. Several states have implemented legislation that broadens the notification system. To be truly effective, the General Assembly should pass legislation to extend this program beyond law enforcement. Another successful program is locally based triads. Triads are composed of representatives from law enforcement, the seniors and community groups on a local level.

Additionally, there are products available that aid in the location of missing endangered adults. Consideration should be given to requiring the Illinois Department of Public Health to seek grant funding for locator devices or requiring the Illinois Department of Healthcare and Family Services or the Illinois Department on Aging to provide locator devices to all eligible clients with dementia. Emergency home response systems are inappropriate for this population.

⁵ PA 094-0145, effective January 1, 2006.

Research Subcommittee

Introduction

This subcommittee's responsibility was to identify "state support of Alzheimer's research through Illinois universities and other resources." The review was somewhat limited to the Alzheimer's Disease Research Act, for reasons explained in the rationale which follows. The Alzheimer's Disease Research Act (410 ILCS 401) allows taxpayers to contribute to the Alzheimer's Research Fund through their state income tax return. The funds are distributed by the Illinois Department of Public Health to encourage research for the purpose of finding a cure for Alzheimer's disease.

Recommendation 1

Develop strategies to attract, grow and track Alzheimer's research funding in Illinois through Alzheimer's research centers, universities and colleges, not-for-profit organizations and other stakeholders.

- The state/Department/advisory committee should actively pursue donations and other sources of funds other than the Income Tax Check Off to increase available state research funds such as bequests, other state or federal funding, or other grants.
- Review the strategies used by other states to leverage additional research dollars and design a plan to be presented to the committee for consideration as soon as possible.
- Protect the Alzheimer's Disease Research Fund from fund sweeps.
- Actively promote the state income tax donations and other donations and contributions to increase the amount of research funding.

Recommendation 2

Develop strategies to protect the Alzheimer's Disease Research Fund.

Recommendation 3

Review and, if necessary, restructure the Alzheimer's Disease Advisory Committee to make it a more pertinent part of Alzheimer's policymaking in the state and clearly outline these responsibilities in statute and develop rules that may extend its responsibilities.

- The committee is not mandated to conduct grant reviews. Study the feasibility for another entity or subcommittee to take on this role to allow the committee to devote its resources to adopt the recommendations of the 93rd General Assembly Legislative Task Force on Alzheimer's Disease, including oversight and evaluation of the services provided by the various state agencies.
- Review the committee's progress in meeting its responsibility to review "all state programs and services provided by state agencies directed toward persons with Alzheimer's disease and related dementias, and recommend changes to improve the state's response to this serious health problem.
- Review the committee's progress to consult with the Department to prepare an Alzheimer's Disease Assistance Plan "to guide research, diagnosis, referral and treatment services within each service areaSuch plan shall indicate any research programs being conducted and the status, results, costs and funding."
- Update the Alzheimer's Disease Research Act and 410 IAC 504/6 which establishes the committee.

Rationale

State support of Alzheimer's research through Illinois universities and other resources is difficult to quantify. (If capturing information would serve a useful purpose, such as generating federal matching funds, then the Department, in cooperation with the committee or a subcommittee of the committee, should develop a methodology to do so.) Because the amount of state-funded research, support for the three clinical funds⁶ is already available and it is unnecessary to do these calculations.

This subcommittee report is limited to the most direct source of research dollars, those in the Alzheimer's Disease Research Act Fund.

In the Alzheimer's Disease Research Act, the Department was given the responsibility of establishing a program that included the award of grants to encourage research for the purpose of finding a cure for Alzheimer's disease. The primary source of funding comes through a state income tax donation. To date, the grant program has been funded entirely through the income tax donations. A total of 142 research projects have been funded, many providing start up ("seed") monies that leads to external funding. A system is not in place to track the follow up of previous grantees and their continued research.

The Department has promulgated rules to establish criteria for the determination of awards and distribution of grants (see 77 IAC 710.210, 220, and 230); however nothing precludes the Department from amending these rules as necessary. Any entity may petition for a rulemaking change, or the advisory committee could make such a recommendation to the committee. Rules, unlike statutes, are generally easier to amend.

The Department has delegated responsibility for reviewing the grant proposals and recommending those to be funded to the Alzheimer's Disease Advisory Committee. The Committee follows the rules established by the Department when making its recommendations for grant funding. Advisory committee members have themselves discussed at open meetings other possible ways to peer review all grant requests from forming subcommittees to delegating the responsibility for a first review to another entity.

Under the research act, additional donations to this fund also can be used for grant awards, although additional donations are available. It does not appear that any additional funding beyond the state income donations off have been obtained.

Although this report is limited to research, it is unclear if the committee is meeting its' responsibilities under the act, including "all state programs and services provided by state agencies that are directed towards persons with Alzheimer's disease and related dementias, and recommend changes to improve the state's response to this serious health problem." The

⁶ The other funds are the Alzheimer's Disease Clinical Fund, the Alzheimer's Disease Center Expanded Clinical Fund, and the Alzheimer's Disease Center Independent Clinical Fund. Notably all three of these funds are protected from funds sweeps but they are dependent each year upon an appropriation from the General Assembly. The Alzheimer's Disease Research Act is not dependent upon general appropriations, but has a specific funding source. It is problematic, however, that the fund is not protected from fund sweeps.

advisory committee also is tasked to consult with the Department in the preparation of an Alzheimer's Disease Assistance Plan to "guide research, diagnosis, and referral and treatment services within each service area. Such plan shall indicate any research programs being conducted and the status, results, costs and funding." The 2003 Alzheimer's Disease Task Force suggested additional responsibilities that the committee could undertake⁷.

Special Care Units, Assisted Living and Nursing Homes Subcommittee

Introduction

This subcommittee studied licensed or certified entities recognized as "Alzheimer's Special Care Units or Centers" and other entities indicating that they provide Alzheimer's or dementia care. Recommendations are followed by rationale. Facts and figures are attached as Appendix A.

Recommendation 1

Extend the applicability of the Alzheimer's Special Care Disclosure Act.

- Amend the applicability of the Alzheimer's Special Care Disclosure Act to include other types of residential facilities, such as supportive living facilities certified by the Illinois Department of Health and Family Services.
- Change the name of the disclosure act to the Alzheimer's Disease and Related Dementias Care Act.
- Develop a plan to require compliance with the Alzheimer's Disease and Related Dementias Care Act by all entities providing housing and service to persons with Alzheimer's diseases or related dementias.
- Phase in, by 2012, compliance with the Alzheimer's Disease and Related Dementias Care Act by all entities providing housing and service to persons with Alzheimer's disease or related dementias.

Recommendation 2

Raise the standards of care for entities providing care and services to persons with Alzheimer's disease or related dementias.

- Update and revise regulations of the Alzheimer's Special Care Disclosure Act, Subpart U (references applicability, admission criteria, assessment and care planning, ability-centered care, activities, staffing, environment, quality assessment and improvement and variances to enhance residents' quality of life), Alzheimer's Special Care Unit or Center Providing Care to Persons with Alzheimer's Disease or Other Dementia, as necessary to include additional criteria to update the standards based upon new research.
- Require compliance with the Subpart U by all entities subject to the Alzheimer's Special Care Disclosure Act and the Alzheimer's Disease and Related Dementias Act.

Recommendation 3

⁷ Suggestion 4 from the 2003 Legislative Task Force Report: "The function of this committee should be expanded to include oversight and evaluation of the services provided by the various state agencies and to solicit additional findings and recommendations for improving state programs and services."

Require improved accountability for care and treatment for persons living in Special Care Units and all other entities caring for persons with Alzheimer’s disease and related dementias.

- Require all Departments that license or certify entities with Alzheimer’s Special Care Units to standardize the disclosure report required under the act,
- Require that all entities subject to the act and the departments must make the disclosure reports available and accessible to current and prospective residents, and the public.
- Require all departments to make this information available and accessible to the public.

Recommendation 4

Require more accountability from Special Care Units and other entities caring for persons with Alzheimer’s disease and related dementias.

- Design a structure to review transfers/discharges of persons with Alzheimer’s disease or related dementias in Alzheimer’s Special Care Units or Centers. These entities must demonstrate staff is trained to provide appropriate behavioral interventions and medications and these interventions have been tried and have failed.
- Apply more stringent transfer/discharge procedures for all persons with Alzheimer’s disease or related dementias residing in entities subject to the Alzheimer’s Special Care Disclosure Act not residing in the special unit or center. These entities must demonstrate staff is trained to provide appropriate behavioral interventions and these interventions have been tried and have failed.
- Apply more stringent transfer/discharge procedures for persons with Alzheimer’s disease or related dementias residing in any licensed or certified residential entity. These entities must provide proof that staff has been trained in appropriate behavioral interventions prior to the transfer/discharge.
- Limit the number of days that a person with Alzheimer’s disease or related dementias may be absent from the entity in cases of transfers/discharges for behavioral issues.

Recommendation 5

Create a new category, Special Care Supportive Living Facility, or provide a Medicaid waiver to assisted living facilities to serve persons with Alzheimer’s disease or related dementias and low income.

Rationale

The Special Care Disclosure Act only applies to an entity licensed under the Nursing Home Care Act, the Community Living Facilities Licensing Act, the Life Care Facilities Act, and the Assisted Living and Shared Housing Act that “holds itself out” as providing specialized Alzheimer’s care in a unit or center. Such entities must file a disclosure report with Illinois Department of Public Health when obtaining an initial or renewal license. .

The disclosure reports also must be made available to actual or potential clients; however, there is no publically available list of nursing facilities that meet the requirements of the act either on the Department’s Web site or from the Department. The Department does maintain a list of licensed assisted living and shared housing establishments on its Web site

http://www.idph.state.il.us/healthca/assisted_living_list.htm. On the list, a “*” denotes entities “contains designated Alzheimer’s units.” No further information is provided with the list.

The disclosure act contains many loopholes that this subcommittee suggests closing including but not limited to the following:

- There are no statutory quality, training, or physical environmental standards for establishments in the disclosure act.
- The information required in the disclosure report is self-reported by establishments, and its contents are not reviewed by the Department. The Department simply notes whether a disclosure report has been filed when an establishment applies or renews its license or certification.
- Any entity can advertise or otherwise market their Alzheimer's care services as long as they do not use or infer that they are operating an "Alzheimer's Special Care Units or Centers." They are permitted to use the terms "Alzheimer's" and/or "dementia" as long as they do not indicate that they provide "specialized Alzheimer's care."
- Only entities designated as Alzheimer's Special Care Units or Centers (by virtue of filing the disclosure report) may use the term "Alzheimer's Special Care" in promotional and other materials; however, some establishments holding themselves out as providing special Alzheimer's care appear to routinely discharge residents with behavioral issues. These discharges occur because the entity is unable or unwilling to deal with common dementia-related behavioral issues, the very thing they claim they do when they hold themselves out as Alzheimer's Special Care Units or Centers.

When the act's carefully written and negotiated rule became part of the Nursing Home Care Act regulations (77 IAC 300), the rule was imposed on establishments subject to the act. These requirements are commonly referred to as the "Subpart U rules" (Alzheimer's Special Care Unit or Center Providing Care to Persons With Alzheimer's Disease or Other Dementia). Subpart U includes admission criteria for the Special Care Units; resident assessments and care planning; provision for ability-centered care; activity programming; staffing requirements that include required orientation and training; environment of the unit; quality assessment and improvement; and variances to enhance residents' quality of life.

- Subpart U applies only to facilities subject to the Alzheimer's Special Care Disclosure Act, meaning it applies only to facilities that "hold themselves out" as providing specialized Alzheimer's care in a center or unit of the facility.
- Most establishments provide care for persons with Alzheimer's disease and related dementias, however these establishments and parts of establishments are not required to meet the Subpart U requirements.

There are several classes of residential entities, such as supportive living facilities (SFL) certified by the Illinois Department of Healthcare and Family Services that are not subject to the act. SLFs are staffed for residents who require minimal supervision/care in an apartment setting. Residents with moderate to severe dementia should not be admitted to these facilities without specific changes to the rules.

It has been noted that most establishments care for persons with Alzheimer's disease or related dementias. These entities often transfer or discharge these persons due to behavioral issues. These persons are denied readmission to the entity.

A Legislative History Addressing Alzheimer’s Disease and Related Dementias

“Those who cannot remember the past are condemned to repeat it....”⁸

-George Santayana (1863–1952)

The history of the state’s actions concerning Alzheimer’s disease and related disorders follows. This is important because, while a new plan is being presented, recommendations made in other state Alzheimer’s reports have yet to be implemented. The recommendations included in this report do not minimize the importance of these recommendations. They should be read in concert with the recommendations in this state plan.

This state plan is the result of a collaborative effort by Alzheimer’s researchers, academics, health care providers, the Alzheimer’s Disease Assistance Centers, associations concerned about the past and future of this rapidly spreading disease, and other citizens of the state.

In 1984, the House Appropriations Committee and the Legislative Research Unit collaborated on a major conference that generated an 11-bill legislative package which became known as the “Alzheimer’s Initiative” (419 ILCS5) that was approved unanimously in 1985. The legislation required that by January 1, 1987, and every three years thereafter, the Department shall prepare a State Alzheimer's Disease Assistance Plan in consultation with the advisory committee to guide research, diagnosis, referral and treatment services within each service area described by the Department.

From 1987 through 2007, Alzheimer’s disease state plans were routinely developed and submitted to the Governor and General Assembly every three years.

In 2003, a Legislative Task Force on Alzheimer’s Disease was created to obtain a current snapshot of the status of the Alzheimer’s initiative and to receive updated information and recommendations for ensuring the state will be able to respond to the rise in the number of people who will be affected (HJR 14).

In 2007, the General Assembly passed Senate Joint Resolution 43 to require the Alzheimer’s Disease Advisory Committee to provide a comprehensive Alzheimer’s Disease and Other Related Dementias State Plan to the Governor and the General Assembly no later than January 1, 2009.

Responding to SJR 43, the Alzheimer’s Disease Advisory Committee created seven subcommittees (as outlined in the resolution) to examine various aspects of the current system and the impending crisis. Each subcommittee was chaired by a member of the committee. Other subcommittee members were chosen for their knowledge and expertise. These subcommittees met in person and by telephone to develop this state plan.

As a result of SJR 43, the Alzheimer’s Disease Advisory Board refocused the Alzheimer’s Disease and Other Related Dementia State Plan to review and study the extent of the impending

⁸ GEORGE SANTAYANA, *The Life of Reason*, vol. 1, chapter 12, p. 284 (1905).

Alzheimer's crisis, the state's current capability to meet this crisis, and to propose state action to prepare for and respond to these challenges. The Alzheimer's Disease Advisory Committee created seven subcommittees (as outlined in the resolution) to examine the following areas:

- 1) Trends in the state Alzheimer's population and needs, including the changing population with dementia, including but not limited to:
 - a. State role in long-term care, family caregiver support and assistance to persons with early stage and early on-set Alzheimer's
 - b. State policy regarding persons with Alzheimer's and developmental disabilities
- 2) Existing services, resources and capacity, including, but not limited to:
 - a. The type, cost, and availability of dementia services
 - b. The capacity of public safety and law enforcement to respond to person's with Alzheimer's
 - c. The availability of home and community-based resources for persons with Alzheimer's and respite care to assist families
 - d. An inventory of long-term care special dementia care units
 - e. The adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's disease and related dementias
 - f. Assisted living residential options for persons with dementia
 - g. State support of Alzheimer's research through Illinois universities and other resources
 - h. Needed state policies and responses, including, but not limited to, recommendations for the provision of clear and coordinated services and support to persons and to families living with Alzheimer's and related disorders and ways to address any identified gaps in service

The seven subcommittees were:

- Alzheimer's Disease Assistance Center Review
- Geriatric-psychiatric Units
- Home and Community Based Resources
- Population and Trends
- Public Safety and Law Enforcement
- Research
- Alzheimer's Special Care Units (Assisted Living and Nursing Homes)

The state and federal government used overwhelming manpower and financial resources to create plans to address possible threats from avian and pandemic flu epidemics. Alzheimer's will soon become a real, not a possible crisis of epidemic proportions. This state plan includes recommendations that should become a concrete legislative initiative to be adopted during the first year of the 96th session of the General Assembly.

1984 Legislative Alzheimer's Initiative

Section 410 ILCS 5) provided that one of these initiatives was the development of a written State plan every three years beginning on January 1, 1987. The contents of the state plan were to indicate any research programs being conducted and the status, results, costs and funding sources

of such programs. Materials included in the state plan were to indicate the number of persons served, the extent of services provided, and the resources required for the delivery of services through the ADA networks established under this act; and to identify and describe the duties and accomplishments of each Regional ADA Center, the primary Alzheimer's providers and other various providers of service within the ADA network of the described service area.

It appears that written state plans were developed every three years, from 1987 through 2007. These state plans contained a thorough review of committee and Alzheimer's Disease Research Center accomplishments. This approach may have been satisfactory in the past, but now a proactive approach is needed. The state plan can no longer be a document that reiterates past activity.

The 2003 Legislative Task Force on Alzheimer's Disease Committee

In 2003, in response to House Joint Resolution 14, the Legislative Task Force on Alzheimer's Disease, composed of eight legislators, prepared another report to the General Assembly. The report noted "Illinois expects to respond in the most appropriate and most effective way to this growing health problem, state agencies and their affiliates must devote additional resources and strengthen their resolve." The Legislative Task Force concluded that "considering the consequences, the state cannot be complacent about the current effort. Illinois must renew its commitment and develop a more aggressive state plan and ensure that the framework of programs and services established by the 84th General Assembly [dubbed the "Alzheimer's Initiative] is functioning and capable of meeting the challenge of this serious public health problem."

While not specifically entitled "Recommendations," the 2003 report offered a series of "Suggestions," most of which have not been resolved even to this day:

Suggestion 1. The Alzheimer's Disease Assistance Act (410 ILCS 405/2) should be updated.

Alzheimer's Disease Assistance Centers

These centers were created to establish a program for the conduct of research regarding the cause, cure and treatment of Alzheimer's disease and related disorders" and through Regional Alzheimer's Disease Assistance Centers and a statewide regional and community-based services to "provide for the identification, evaluation, diagnosis, referral and treatment of victims of such health problems." State grants are provided to the regional centers to help fund research and provide service to Alzheimer's patients and their families.

Suggestion 2: "...the General Assembly should not only stabilize the existing level of funding -- as recently done through the restoration of the Governor's veto of funding for fiscal year 2004 -- but provide additional funding for the fiscal year 2005."

Suggestion 3. "The past year's experience, especially the Governor's veto of the original appropriation, underscores the need to implement a more specific and dedicated methodology. The General Assembly should restructure financing for the centers under the Excellence in Academic Medicine Act (30 ILCS 775/)."

The Alzheimer's Disease Advisory Committee (410 ILCS 405/6) is comprised of 21 voting members and five nonvoting members. The primary function of the committee is to review the annual Alzheimer's Disease State Plan prepared by the Illinois Department of Public Health.

Suggestion 4. “The function of this committee should be expanded to include oversight and evaluation of the services provided by the various state agencies and to solicit additional findings and recommendations for improving state programs and services.”

Public Act 91-744 required state agencies to “develop specialized training and experience criteria for persons who provide health or home care to victims of Alzheimer's disease or other dementia-related disorders” and “to study the effectiveness of certifying an appropriate private certifying body for persons providing health or home care.”

Suggestion 5: “Without delay, the department should provide funding to issue the dementia training manual for the demonstration project, and target additional training on dementia specific issues.”

The report recognized the statewide shortage of adult day care in Illinois, attributable to the extent of the availability of state funding and the adequacy of the rates paid by the Illinois Department on Aging to adult day providers. Despite several increases, adult day services continue to close due to lack of funding at the same time that the demand for these services is expanding.

Suggestion 6: The duties of the Center for Minority Health Services “should be revised to include advocacy and promotion of the increased risk of Alzheimer's disease among minority populations.”

Suggestion 7: “...the state should allow for an income tax credit equal to 15 percent of the premium costs of long-term care insurance.”

Suggestion 8. “Initiate a pilot program, through the Illinois Department of Public Health, to expand information and assistance services currently available via the 1-800-number of the Alzheimer's Association....to demonstrate that people should be able to contact one central location to seek help and obtain answers to their questions.”

APPENDIX A Senate Joint Resolution 43 of the 95th General Assembly
Illinois General Assembly - Full Text of SJR0043

09500SJ0043 EnrolledLRB095 11855 KBJ 34916 r

1SENATE JOINT RESOLUTION NO. 43

2 WHEREAS, Alzheimer's disease is a slow, progressive
3disorder of the brain that results in loss of memory and other
4cognitive function and eventually results in death; and

5 WHEREAS, Because Alzheimer's is accompanied by memory
6loss, poor judgment, changes in personality and behavior, and a
7tendency to wander, individuals with this disease are at
8increased risk for accidental injury, getting lost, abuse,
9neglect, and exploitation; and

10 WHEREAS, With one in 10 people over age 65 and almost one
11in every 2 people over 85 having Alzheimer's disease or a
12related dementia, over the past 10 years, the number of
13Illinoisans with Alzheimer's and related dementias has risen
14dramatically to the point that today over 210,000 people are
15affected; and

16 WHEREAS, As the baby boom generation enters the age of
17greatest risk for Alzheimer's, by 2025 their number in Illinois
18is expected to increase to over 239,000; and

19 WHEREAS, Alzheimer's disease takes an enormous toll on
20loving family members, with an estimated one in 4 acting as
21caregivers for each individual with the disease; and

09500SJ0043 Enrolled- 2 -LRB095 11855 KBJ 34916 r

1 WHEREAS, Caregivers for individuals with Alzheimer's watch
2closely the deleterious effects of the disease and often suffer
3more stress, depression, and health problems than caregivers of
4people with other illnesses; and

5 WHEREAS, Alzheimer's disease is considered to be early
6onset if an individual is younger than 65 when symptoms first
7appear, and early onset Alzheimer's can strike someone as early
8as their 30s, 40s, and 50s, with new data showing there may be
9half a million Americans under age 65 who have dementia or
10cognitive impairment at a level of severity consistent with
11dementia; and

12 WHEREAS, The Alzheimer's Disease Assistance Act created
13the Alzheimer's Disease Advisory Committee composed of 21
14members to review all State programs and services provided by
15State agencies that are directed toward persons with
16Alzheimer's disease and related dementias and to recommend
17changes to improve the State's response to this serious health
18problem; and

19 WHEREAS, The 93rd General Assembly created the Legislative
20Task Force on Alzheimer's Disease pursuant to House Joint
21Resolution 14; that task force conducted hearings which
22included each of the State agencies having primary

09500SJ0043 Enrolled- 3 -LRB095 11855 KBJ 34916 r

1responsibility for implementing the "Alzheimer's Initiative"
2of the 84th General Assembly when this matter was given a high
3priority nearly 20 years ago; the agencies were instructed to
4provide an update on the progress made in implementing that
5initiative to determine whether the programs and services
6developed by State agencies reflect the original priority; the
7reports of the agencies did not demonstrate any particular
8progress, nor priority commensurate with the original interest
9and intent of the General Assembly; and

10 WHEREAS, The 93rd General Assembly Legislative Task Force
11on Alzheimer's Disease recommended that the function of the
12statutory Alzheimer's Disease Advisory Committee should be
13expanded to include oversight and evaluation of the services
14provided by the various State agencies and to solicit
15additional findings and recommendations for improving State
16programs and services; and

17 WHEREAS, The State of Illinois must not be complacent and
18must renew its commitment to develop a more aggressive State
19plan to ensure that the framework of programs and services to
20help Illinoisans with Alzheimer's and other related dementia
21are functioning and capable of meeting the challenge of this
22serious public health problem among Illinoisans; therefore, be
23it

09500SJ0043 Enrolled- 4 -LRB095 11855 KBJ 34916 r

1 RESOLVED, BY THE SENATE OF THE NINETY-FIFTH GENERAL
2ASSEMBLY OF THE STATE OF ILLINOIS, THE HOUSE OF REPRESENTATIVES
3CONCURRING HEREIN, that the Department of Public Health

4immediately comply with the Alzheimer's Disease Assistance Act
5in activating the Alzheimer's Disease Advisory Committee and
6ensuring that it fulfills the requirement of reviewing all
7State programs and services provided by State agencies directed
8toward persons with Alzheimer's disease and related dementias
9and recommending changes to improve the State's response to
10this serious health problem; and be it further

11 RESOLVED, That the Department of Public Health, in
12conjunction with the Alzheimer's Disease Advisory Committee,
13assess the current and future impact of Alzheimer's disease on
14the people of this State, examine the existing services and
15resources addressing the needs of persons with Alzheimer's,
16their families, and caregivers, and develop a strategy to
17implement an Alzheimer's Disease and Other Related Dementia
18State Plan in response to this public health crisis; and be it
19further

20 RESOLVED, That the Alzheimer's Disease Advisory Committee
21shall include in its Alzheimer's Disease and Other Related
22Dementia State Plan an examination of the following:

23 (1) trends in the State Alzheimer's population and
24 needs, including the changing population with dementia,

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1 including but not limited to:

2 (a) the State role in long-term care, family
3 caregiver support and assistance to persons with
4 early-stage and early on-set Alzheimer's;

5 (b) State policy regarding persons with
6 Alzheimer's and developmental disabilities;

7 (2) existing services, resources, and capacity,
8 including but not limited to:

9 (a) the type, cost, and availability of dementia
10 services;

11 (b) the capacity of public safety and law
12 enforcement to respond to persons with Alzheimer's;

13 (c) the availability of home and community-based
14 resources for persons with Alzheimer's and respite
15 care to assist families;

16 (d) an inventory of long-term care special
17 dementia care units;

18 (e) the adequacy and appropriateness of
19 geriatric-psychiatric units for persons with behavior
20 disorders associated with Alzheimer's and related
21 dementias;

22 (f) assisted living residential options for
23 persons with dementia;

24 (g) State support of Alzheimer's research through
25 Illinois universities and other resources;

26 (3) needed State policies and responses, including,

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1 but not limited to recommendations for the provision of
2 clear and coordinated services and support to persons and
3 families living with Alzheimer's and related disorders and
4 ways to address any identified gaps in service; and be it
5 further

6 RESOLVED, That the Department on Aging, in cooperation with
7the Department of Public Health and the Department of
8Healthcare and Family Services, shall provide support staff to
9the Alzheimer's Disease Advisory Committee and shall be
10responsible for preparing any necessary materials and reports
11in conjunction with the work of the Committee; and be it
12further

13 RESOLVED, That the Alzheimer's Disease Advisory Committee
14shall provide an Alzheimer's Disease and Other Related Dementia
15State Plan to the Governor and the General Assembly no later
16than January 1, 2009; and be it further

17 RESOLVED, That suitable copies of this resolution be
18delivered to the Governor, the Director of Aging, the Director
19of Public Health, and the Director of Healthcare and Family
20Services.

APPENDIX B Members of the Alzheimer's Disease Advisory Committee

Rhonda Clancy, Coordinator, Illinois Department of Public Health

David Bennett, M.D., Rush University Medical Center

Tom Berkshire, Family Member Representative

Janice Cichowlas, Ph.D., J.D., Illinois Department on Aging

Erna Colborn, President/CEO, Alzheimer's Association -- Greater Illinois Chapter

Rod Curtis, M.D., Illinois Department of Human Services

Jerome Epplin, M.D., Litchfield Family Practice

Judith E. Hertz, R.N., Ph.D., Northern Illinois University

Larry Lindahl, M.D., Order of St. Francis Institute on Aging

Dennis McManus, M.D., Order of St. Francis Healthcare

M. Marsel Mesulam, M.D., Northwestern University

Mary Milano, M.D., Illinois Guardianship and Advocacy Commission

Darby Morhardt, M.S.W., Northwestern University

Robert Moss, M.D., Advocate Lutheran General Hospital

Mary A. Nagy, R.N., M.S., Family Member Representative

Donald Pearson, M.D., General Public Representative

Christopher Randolph, Ph.D., Loyola University Medical Center

Sharon Roberts, R.N., B.S.N., N.H.A., M.A., Lake County Health Department

Phyllis L. Schwebke, LNHA, River Bluff Nursing Home

John M. Smith, Egyptian Area Agency on Aging, Carterville

Shirley Whitcup, R.N., B.S.N., Illinois Department of Healthcare and Family Services

Orlinda Workman, L.S.W., M.S.W., Passavant Hospital

APPENDIX C Members of the Alzheimer's Disease Advisory Committee Subcommittees

Center Review

Chair: Christopher Randolph, Ph.D. (Alzheimer Disease Advisory Committee)

Tom Ala, M.D. , Southern Illinois University

David Bennett, M.D. (Alzheimer Disease Advisory Committee) Rush University

Erna Colborn, (Alzheimer Disease Advisory Committee), Alzheimer's Association-Greater Illinois Chapter

Dennis McManus, M.D. (Alzheimer Disease Advisory Committee)

M.-Marsel Mesulam, M.D. (Alzheimer Disease Advisory Committee) Northwestern University

Darby Morhardt, M.S.W. (Alzheimer Disease Advisory Committee) Northwestern University

Maggie Schaver, Southern Illinois University

Julie Schneider, M.D., Rush University

Geriatric-Psychiatric Units

Chair Orlinda Workman, L.S.W., M.S.W. (Alzheimer Disease Advisory Committee)

Zoe Arvanitakis, M.D., Rush University

Mary J. Elsner, J.D., Morton Grove

Charlotte Kauffman, Illinois Department of Human Services

Kathy Lee (Memorial Medical Center, Springfield)

Bernice Marinelli, Anam Care Inc., Rockford

Christopher Randolph, Ph.D. (Alzheimer Disease Advisory Committee)

Debbie Reed, M.D. (Northwestern University)

David Resch, Southern Illinois University

Raj Shah, M.D., Rush University

Sandy Swantek, M.D., Northwestern Hospital

Home and Community Based Resources

Co-Chair: Janice Cichowlas, Ph.D., J.D., (Alzheimer Disease Advisory Committee) Illinois Department on Aging

Co-Chair: Carolyn Hicks (Alzheimer Disease Advisory Committee)

Jane Kessler, Illinois Department of Public Health (retired)

Greg Kyrouac, Southern Illinois University

Nancy Larson, J.D., Harter & Larsen, LLC, Belleville

Barbara Lokaitis, Southern Illinois University

Darby Morhardt, M.S.W. (Alzheimer Disease Advisory Committee) Northwestern University

Ann Popovich, Southern Illinois University

Maria Schmidt, Alzheimer's Association – Greater Illinois Chapter

Jerry Schroeder, Alzheimer's Association- Greater Iowa Chapter, Davenport, Iowa

Todd Shackelford, West Central Illinois Area on Aging, Quincy

John Smith (Alzheimer Disease Advisory Committee) Egypton Area Agency on Aging, Carterville

Populations, Trends and Needs

Chair: Dennis McManus, M.D. (Alzheimer Disease Advisory Committee)

Lisa Barnes, Ph.D., Rush University

Judy Buchanan, Alzheimer's Association- Greater Illinois Chapter, Bloomington
James Dearing, Alzheimer's Association -- Greater Illinois Chapter, Springfield
Darby Morhardt, M.S.W. (Alzheimer Disease Advisory Committee) Northwestern University
Ann Popovich, Southern Illinois University
Don Scott, Southern Illinois University
John Smith (Alzheimer Disease Advisory Committee)
Pam Smith, Rush University
Orlinda Workman, L.S.W., M.S.W. (Alzheimer Disease Advisory Committee)
Ron Zec, Ph.D., Southern Illinois University

Public Safety and Law Enforcement

Chair: Mary Nagy, R.N., M.S. (Advisory Committee)
Tom Ala, M.D., Southern Illinois University
Karen Lowe Graham, Rush University Medical Center
Maria Schmidt, Alzheimer's Association—Greater Illinois Chapter (Springfield)
Barbara Lokaitis, Southern Illinois University
Mary Milano, M.D., Illinois Guardianship and Advocacy Commission, Advisory Committee
Ron Zec, Ph.D., Southern Illinois University

Research

Chair: David Bennett, M.D. (Alzheimer Disease Advisory Committee), Rush University
Greg Brewer, Southern Illinois University
Sandy Burgener, University of Illinois
Madelyn Iris, Ph.D., Leonard Schanfield Research Institute, CJE, Chicago
M.Marsel Mesulam, M.D. (Alzheimer Disease Advisory Committee) Northwestern
Christopher Randolph, Ph.D. (Alzheimer Disease Advisory Committee) Loyola
Gail Shaw, M.P.A., Care Coordinator, St. John's Home and Community Care, Collinsville
Bob Struble, Ph.D. Southern Illinois University
Robert Wilson, Ph.D., Rush University

Special Care Units, Assisted Living and Nursing Homes

Chair: Erna Colborn (Alzheimer Disease Advisory Committee), Alzheimer's Association - Greater Illinois Chapter
Paula Connell, Pioneer Coalition, B.S.N., R.N., West Central Illinois Area Agency on Aging, Quincy
Jerome Epplin, M.D. (Alzheimer Disease Advisory Committee)
Susan Frick, Rush University
Stuart Gaines, Alzheimer's Association-Greater Illinois Chapter, Rockford
Greg Kyrouac, Southern Illinois University
Ann Popovich, Southern Illinois University
Phyllis Schwebke, L.N.H.A. (Alzheimer Disease Advisory Committee)
Lisa Vandermark N.A.D.C., Presbyterian Homes
(alternate Celia Berdes, Ph.D., N.A.D.C.)