To: Members of the Delaware General Assembly  
From: Rita M. Landgraf, Secretary Delaware Health and Social Services  
Re: Long Term Care Housing Task Force  
Date: April 19, 2010

Attached please find the Final Report of the Long Term Care Housing Task Force. The Task Force membership included community advocates, funders, educators, legislators, members of the Department of Health and Social Services, members of the healthcare and long term care industry and consumers.

In June of 2008, Delaware’s General Assembly passed legislation that included the establishment of a Long Term Care Housing Task Force to examine the housing and care needs of a growing and aging Delaware population. The introductory language in Senate Bill 300 states by forming the Long Term Care Housing Task Force the Legislature was

“Recognizing Delaware has an obligation to establish a rational long term care system to prevent expensive and premature institutionalization and to insure Delaware’s senior and disabled population who are able to remain in their homes and community should receive services needed to remain as independent as possible.”

The Long Term Care Housing Task Force has completed its work and is pleased to provide relevant findings and observations which are highlighted within this report.

I would like to thank our fellow Task Force members for the diligence, dedication, and commitment they demonstrated in carrying out the challenging work before us. Several of them engaged in individual research that provided an important framework for discussion and the basis for some of the recommendations presented in this document. Additionally, the insight that each person brought from his or her diverse professional roles served to complement the work of the group as a whole and allowed for thoughtful questioning and debate.

We believe that through this thoughtful exchange, we are able to present a comprehensive plan of recommendations, which are intended to further enhance the quality of long term care services in Delaware.

Sincerely,
Rita M. Landgraf
Secretary
Long Term Care Housing Task Force
Established by Senate Bill 300 on June 30, 2008

Final Report to the Delaware General Assembly
– April 19, 2010

“Senior Americans, whether rich, poor, or somewhere in the middle, face many barriers to an old age in which very basic human desires for physical safety, appropriate health care, and maximal independence are met. For some, crucial family supports will disappear as they outlive spouses or children move to distant places. For others, limited resources will prevent them from identifying and purchasing needed services. Many will lose their homes—long a symbol of their independence—due to rising property taxes and maintenance costs. Living alone, isolated from services and perhaps coping with disabilities that prevent social interactions, a large and growing number of seniors will face triple jeopardy: inadequate income, declining health and mobility, and growing isolation.”

-Executive Summary, A Quiet Crisis in America
A Report to Congress by the Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century
Introduction

In June of 2008 Delaware’s General Assembly passed legislation that included the establishment of a Long Term Care Housing Task Force to examine the housing and care needs of a growing and aging Delaware population. The introductory language in Senate Bill 300 states by forming the Long Term Care Housing Task Force the Legislature was

Recognizing Delaware has an obligation to establish a rational long term care system to prevent expensive and premature institutionalization and to insure Delaware’s senior and disabled population who are able to remain in their homes and community should receive services needed to remain as independent as possible.

With this charge, the Long Term Care Housing Task Force met four times in 2009 and conducted our final meeting in March, 2010, to discuss aspects of Long Term Care, including the changing demographic makeup in Delaware that will find more Delawareans of older age; a lack of community choice for individuals, including adults with disabilities regardless of age, to receive long term care services in their home or community; a desire by individuals to receive care in the most independent setting possible; and, finally, a lack of community resources available to meet the care needs and desires of Delawareans.

The members of the Task Force were an array of stakeholders involved in the Delaware long term care arena (a complete list of Task Force members is included at the end of this report). In addition to Task Force members, guest speakers were invited to attend the four Task Force meetings to provide additional insight into the challenges and opportunities Delaware faces in the near and not-too-distant future.

The Long Term Care Housing Task Force (hereinafter “Task Force”) has completed its work and is pleased to provide relevant findings and observations which are highlighted within this report. It should be noted that the Task Force considers its work complete as called for in Senate Bill 300, and that it envisions that Delaware and its long term care stakeholders will use Task Force findings to work together in meeting the challenges that Delaware faces.

I. Delaware’s Changing Demographics

The Task Force quantified demographic trends that will significantly impact the supply and demand for long term care services. Mr. Edward Ratledge from the University of Delaware’s Center for Applied Demography and Survey Research shared data that illustrate how Delaware’s changing demographics will impact Delaware’s long term care system. In addition to Mr. Ratledge’s information, studies reviewed by the Task Force provided a snapshot to the challenges Delaware faces. Among the pertinent data:

The total population of Delaware will increase from 600,000 in 1975 to approximately 1,000,000,000 (1 Million) by 2020. It is projected that New Castle County alone will have 600,000 residents by the year 2030, placing pressure on infrastructure, service delivery structure and public funding to meet the needs of a growing population.

Delaware’s population of those age 65 and over will increase by almost 106% between 2005 – 2030 an increase of 123,000 people.

Delaware not only has to adjust for its current aging population, but the state has also experienced a migration of seniors moving to the state in greater numbers. The Census Bureau reports that between 1995 and 2000, 2,679 additional seniors age 65+ moved to Delaware. This is about 25 new residents for every 1,000 current residents. Of additional concern is that about 20% of seniors have significant long-term care needs. For those not residing in a long term care facility, 18% of individuals over age 65 need assistance with everyday activities.

It is estimated that there are 87,000 one-person households in Delaware, most of them older Delawareans. This number is significant when considering that one-person households often have no one to rely upon for support, whether it be doing common household chores, assisting with bill organizing and payment, driving to the grocery store or doctor appointments, or in providing assistance should a health need arise.

In addition, beginning at age 60, the likelihood of hospitalization increases dramatically with men, who are slightly more likely to require hospital care than women. Hospital stays, even if not lengthy, can place a strain on everyday aspects of life that most take for granted.
II. Common Threads of Select Long Term Care Studies

The Task Force conducted a review of several major studies related to long term care (see Summary of Sources at the end of the report). Although each document contained a high level of detail among multiple areas, five common themes were identified among the studies that were important to the work of the Task Force.

Common Themes Among 5 Main Areas

A. The Need for Long Term Care Services

Long term care is essential for individuals who require assistance with Activities of Daily Living (ADLs). The basic ADLs consist of these self-care tasks:

- Bathing,
- Dressing and undressing,
- Eating,
- Transferring from bed to chair, and back,
- Voluntarily control urinary and fecal discharge,
- Using the toilet, and Walking (mobile, not bedridden).

To be considered for acceptance in a long term care facility an individual must have difficulty with at least one ADL. It is estimated that approximately 1.2 million Americans are currently severely impaired and need help with more than 3 daily living activities. Some projections indicate that by 2020 there will be 4.3 million seniors with ADL limitations.

More than four out of ten individuals age 65+ have one or more of the following disabilities that affects their ability to accomplish common tasks of everyday living: sensory, physical, mobility, self-care, and cognitive/mental. In the year 2010, 13% of individuals age 65+ are projected to suffer from Alzheimer’s disease.

However, just because a person requires assistance with one or more ADLs does not mean that it is a requirement to receive care in a facility. Indeed, most individuals report a strong preference to receive care in home or community as opposed to in facility-based care. A recent AARP Delaware study found that 74% of individuals interviewed indicated that they’d prefer to receive long term care in their homes compared to 3% who would prefer a nursing home, or 19% in assisted living facility.

It is estimated that 9.1 million seniors now utilize some level of personal care, ranging from skilled nursing to personal care in the home. Many of these individuals rely on caregiving services provided by family or friends. In the United States, 34 million caregivers age 18 and older were providing unpaid care to friends and family at any given time in 2007. The estimated economic value of the 34 million caregivers was $375 billion in 2007 -- an amount that exceeds Medicaid LTC spending in all states.

In order for people who need care with daily activities to remain in their homes, the ability to access important services will need to be available. The aging population will require greater community capacity to deal with cardiac, oncology, rehabilitation, and geriatric treatment along with ambulatory care centers, acute care facilities, laboratories, and clinics.

B. Housing

The lack of affordable and accessible housing is a major barrier to individuals who wish to remain at home as they age. Almost ½ of all seniors are likely to be considered low income, with about 1/3 paying more than half their income toward housing.

In addition, most seniors will continue to live in homes that they own. By 2020, more than 80% of senior householders will be homeowners, with almost 44% of senior householders age 75+.

Home ownership is a positive thing, for both seniors and the overall economy. Unfortunately, the homes in which seniors live are likely not equipped with Universal Design features that will permit seniors to access all parts of their home.
Universal Design is a term reflecting housing features that enable people of all ages and physical abilities to live comfortably and independently in their homes. Examples of Universal Design elements in a home include wider doorways, lower counter tops, and blocking in walls to allow the easy installation of grab bars to assist individuals in the bathroom and shower. Approximately 20% of those surveyed by AARP in Delaware claim to need major modifications to their homes in order to be able to remain in their existing home as they age. 66% claim to need bathroom modifications such as grab bars and handrails, 59% need access to accommodations such as ramps and chairlifts, 43% need a new roof or new plumbing, 38% need better cooling for summer, and 36% need better heating. About 12% of seniors claim their home is “not well” or “not well at all” able to meet their physical needs as they grow older. In Delaware almost one in five surveyed report that they need to make major repairs, modifications, or changes to their homes to allow them to “age in place”. The most frequently needed modifications are faucet and cabinet adaptations, stair lifts or elevators, bathroom access, ramps, and curb-less or roll-in showers.

C. Transportation

Access to transportation is an essential need for individuals to maintain independence in the community. The ability to have access to grocery shopping, health care, prescription medications, and other activities that increase one’s quality of life (like church services) are top reasons to own a car, to have access to public transportation, to live within walking distance of services, or to have friends or family in close proximity to assist with transportation needs.

Unfortunately, lack of transportation options limit mobility for as many as 50% of older, non-drivers and keep them trapped in their homes. Studies show that one in five Americans age 65 and over do not drive due to declining health, eyesight, physical or mental abilities, concern over safety, and no car or access to a car. In Delaware, with a heavy reliance on car travel, the ability for older Delawareans to remain connected to their community is severely limited because they do not live in close proximity to public transportation.

In order to increase driving options for older drivers many jurisdictions nationwide are designing roads and communities to meet the needs of all drivers. Such changes include widening driving lanes, adding more traffic lights and stop signs, and presenting traffic signs in larger fonts and placed in locations that will make it easy for older drivers to see and read them.

Research estimates that a 75-year-old woman is likely to experience 10 years of non-driving and a man, six years. Fortunately older Delawareans are open to the idea of accessing public transportation. A Delaware AARP survey revealed that 40% of those surveyed agreed they would use the bus if it was more convenient.

D. Other Aspects of Healthy Aging

As individuals approach their elder years, they face other challenges and opportunities typically not present in younger life. These changes in life may impact the well-being of older individuals as they adjust to new social, economic, and health realities.

An AARP report called Beyond 50.05: A Report to the Nation on Livable Communities: Creating Environments for Successful Aging defines successful aging as, “the ability to maintain three key behaviors or characteristics: low risk of disease-related disability; high mental and physical function; and active engagement with life.”

Task Force Member Dr. Veronica Rempushesk from the University Of Delaware School Of Nursing shared that healthy aging is a “combination of genetic makeup, behavior, and environmental factors such as physical, emotional, social, and recreational pathways.”

Both definitions reflect that as one enters the later years of life they often experience a significant role loss. Retirement from decades of working removes job identity and the structured life that typical working years entail. Children are typically adults and have entered a life of independence. Close friends and family have often passed away, moved away, or in poor health.

The adjustment to these new realities can lead to adverse outcomes, including a feeling of non contribution or being of use to society. Dr. Rempushesk’s research findings show that usefulness is a major contributor to vibrant health and a prominent predictor of disability and mortality risk. Those who never or rarely felt useful were more likely to experience an increase of disability or death.
Research also shows that continuing to develop and maintain social connections is associated with enhanced physical and mental health among persons of all ages. Positive self esteem is strengthened and activities like volunteering generate positive emotions such as contentment, satisfaction, and pride. Physical, and intellectual stimulation, and a general feeling of being a contributor to society has been found to boost health, immune functioning, and prevent cognitive decline.

E. Paying for Long Term Care

As we have seen the population of older Delawareans is projected to increase tremendously over the next 20 years. The increase in this segment of the population will cause a corresponding increase in need for long term care services. Unfortunately, the increased demand for services will place pressure on a system heavily reliant on government programs to provide that care.

For example, in 2009 Delaware spent $89 million in state funded only Medicaid institutional care services and $51 million in state funded long term care waiver services that enable individuals to remain in community while they receive care. Nationally, more than 1/3 of Medicaid funds now go to finance long-term care, which will reach half of all Medicaid spending by 2015, according to CMS, the federal agency responsible for the Medicaid program.

Since not everyone qualifies for Medicaid, many people will have to resort to other options when their finances fall short. In 2000, only 18% of senior citizens most likely to use nursing home care had sufficient financial resources to cover 2.5 years in a nursing home. Some seniors will meet their long term care needs by tapping home equity to finance home improvements to increase accessibility and others will relocate to meet their long term care needs. But because long-term care is so expensive, 56% of nursing home residents eventually “spend down” their resources to qualify for Medicaid, which will only exacerbate the pressures on state government to meet demand.

To make matters worse, institutional long term care services costs an average $81,000 per year, compared to about $15,000 per year which represents an average of 2 hours of daily home care cost. In an AARP survey of Delaware residents 35+, 50% of the participants had little to no confidence in their ability to pay for long term care services for themselves or a family member. The survey found that about 40% plan to rely on government programs and about 30% plan to use long-term care insurance.

F. Moving Forward-Possible Solutions to providing increased choice in Long Term Care

**Major state LTC system change generally requires two key elements:**
- Leadership and vision reflecting core values on the part of top state policymakers (state agency officials, governors, and/or legislators) and,
- Participation of major stakeholders, including consumers, providers, state officials, and individuals with disabilities and the groups that represent them.

**Consolidation of LTC Aging and Disability Systems**

The ultimate purpose of a state’s consolidation of its LTC system is to overcome barriers to consumer access to services and supports, and to ensure the availability of real and viable choices to consumers. Consolidating the existing fragmented program areas makes it possible for program administrators and consumers to begin thinking about LTC as a system designed to meet the changing needs of individuals, and not just a system of separate programs. Minnesota, New Mexico, Oregon, Vermont and Washington have either consolidated LTC policies and programs or are in the process of doing so.

**Educate public on the need for LTC planning**

As long-term care costs can seriously weaken one’s ability to enjoy a financially comfortable retirement, it is surprising that many people do not understand who truly pays for long-term care. While many are all too aware of the rising cost of long-term care, a majority is unsure who pays for it. Further, for those who do not plan to purchase a long-term care insurance policy, most of them are unsure or have not thought about how to pay for these services should the need arise. This is especially true for younger respondents (ages 40-49, as over half (53%) have not considered how they would pay for long-term care. About 25% of 60-70 year olds also have no plan regarding how to pay for long-term care. Overall, nearly 30% report not being sure about how to pay for LTC, while nearly 40% admit not having thought about it at all. Ironically, 87% of respondents correctly understand that comprehensive long-term care insurance pays for all forms of long-term care services.
While many respondents can name which services are associated with long-term care, they are largely mistaken when it comes to identifying who will pay for it. (33% thought Medicare would pay, 19% thought disability insurance would pay, 14% thought Health Insurance would pay and 34% thought other.)

It appears that people are not seeking information until they are near or in a situation of needing this type of information. While there have been sporadic improvements in some areas of knowledge and consistency of some misconceptions, most adults have yet to connect-the-dots about their long-term care needs, financing, income protection, and their own decision making and actions to address these issues. An important part of the solution to the long-term care riddle lays in education the public about the realities of long-term care.

The Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) was awarded a three-year grant for the federal Administration on Aging to establish an Aging and Disability Resource Center (ADRC) in Delaware. DSAAPD is working with many private and government partners to develop the resource center.

The three goals of the ADRC
- To provide a highly visible and easily identified source of information on aging and disability-related services
- To provide assistance with care and support planning through effective options counseling and case management
- To facilitate the timely and successful transition of persons who are leaving acute care or other facilities and returning to the community

Investigate Public Financing Options Utilized in Other States for Possible Adoption

Many promising approaches have been instituted by other states as they attempt to address the need for long term services while not sacrificing quality of care. Delaware’s growing aging population, the increased reliance on public programs, and the inability of individuals to afford long term care make it imperative that the State find innovative approaches to provide future services and funding streams to support the demand in the most cost effective way. This may include the adoption of a Medicaid LTC Managed Care program and/or the implementation of PACE. The Program of All-inclusive Care for the Elderly (PACE) model is centered around the belief that it is better for the well-being of seniors with chronic care needs and their families to be served in the community whenever possible. By doing this, PACE meets Olmstead requirements and helps seniors age in the community.

PACE eligibility is set by the Centers for Medicare & Medicaid Services (CMS). PACE serves individuals who are age 55 or older, certified by their state to need nursing home care, are able to live safely in the community at the time of enrollment, and live in a PACE service area. The PACE program is open 24 hours a day, 365 days a year.

Although all PACE participants must be certified to need nursing home care to enroll in PACE, only about 7% of PACE participants nationally reside in a nursing home. If a PACE enrollee does need nursing home care, the PACE program pays for it and continues to coordinate the enrollee’s care.

Collaborate Across State and Local Government

Efforts need to be enhanced in the area of community design, housing, transportation and workforce development across government. A unified focus on the ever changing demographics and a planning process both at the local and state level will enhance mobility and access to service that will promote elder friendly environments.

III. Conclusion

This report has provided an overview of the direction Delaware may pursue in improving access to Home and Community Based Services in Delaware. Increase efforts in community based services will:

1-help to meet the overwhelming desire of Delawareans to age in their home and community versus institutional-based care

2-begin to bring balance to Delaware's Medicaid spending in LTC
3-reduce the premature reliance on the highest cost of care - facility based care, thereby reducing the growth of Medicaid LTC spending

4-advance Delaware’s efforts in meeting Olmstead requirements

5-provide a source of jobs for individuals desiring to provide care and services in home and community settings

6-engage an emerging increase of older and retired Delawareans to help implement home and community based care, such as utilization of volunteer community ombudsmen

While this report is intended to provide information on paths Delaware may take to increase access to community based care, it should be viewed as a beginning, and as a living document. Important improvements to community based services are included in the final Federal Healthcare Reform Bill such as, more equity between financial eligibility standards in community based and facility based care, Community First choice option and expansion of the Money Follows the Person program which educates individuals currently in facilities of their rights to receive community based services if desired and can be supported.

Once a direction on Delaware community based care expansion has been determined a deeper analysis will need to occur, including budget projections and project milestones. Workgroups will be formed by DHSS to implement initiatives, and will include involvement from Delaware’s not-for-profit and business community, including no-cost assistance from Delaware stakeholders. For example, AARP has offered their help in evaluating Medicaid Managed Long Term Care and PACE, and Genworth Financial has expressed interest in helping Delaware move toward a Long Term Care Insurance Partnership Program. St. Francis and Christiana Care Hospitals have expressed interest in evaluating the development of a PACE program(s) in Delaware.

Public/private collaborations will assist the State in developing best practices and provide a natural pathway to community buy-in and implementation. Comprehensive structural change often requires public and political support, which can be engendered through task forces or commissions and the studies and recommendations that emerge from their deliberations. Legislators often follow through on many task force recommendations by requiring the restructuring of state agencies as a first step.

**Long Term Care Housing Task Force Members and Interested Participants**

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<th>Name</th>
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