

## White House Conference on Aging Regional Input Form

### Planning Along the Lifespan END OF LIFE PLANNING

#### General Description

For the past 45 years state and federal governments have passed laws to encourage older adults to complete end-of-life care planning before they become incapacitated due to acute and chronic illnesses. These legal remedies have included the following:

- 1960's - Anatomical Gift Acts
- 1970's - Living Will Acts
- 1980's - Durable Powers of Attorney for Health Care Decisions
- 1990's - Combined Advance Directives and DNR statutes
- 2000's - Physician Orders for Life Sustaining Treatment/Advanced Care Planning

Congress also sought to propagate living wills through the Patient Self-Determination Act which was passed in 1990. The Patient Self-Determination Act requires hospitals to inform patients about advance directives, but empirical evidence suggests that this law has done nothing to significantly increase the use of advance directives.

A little over a year ago the prestigious Hastings Center published a report entitled "Enough: The Failure of the Living Will." The report concludes:

*"First, despite the millions of dollars lavished on propaganda, most people do not have living wills.... Second, people who sign living wills have generally not thought through its instructions in a way we should want for life-and-death decisions. Nor can we expect people to make thoughtful and stable decisions about so complex a question so far into the future. Third, drafters of living wills have failed to offer people the means to articulate their preference accurately.... Fourth, living wills too often do not reach the people actually making decisions for incompetent patients.... Fifth, living wills seem not to increase the accuracy with which surrogates identify patients' preferences."*

The authors of this article recommend that patients seeking to control their future medical care be told about and execute durable powers of attorney. Many area agencies on aging already assist persons in completing these documents. Unfortunately, most older persons and their families wait until it is too late to discuss end-of-life care with their families and complete medical powers of attorney. In many cases, even if these documents have been completed, many health care professionals are unaware of these documents when treatment decisions are made.

The most promising practice to date to encourage and increase end-of-life care planning is "patient-centered advance care planning" pioneered by the Gunderson Lutheran Medical Center in La Crosse, Wisconsin. Patient-centered advance care planning encourages consumers to identify their values and develop goals for end-of-life care with

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questions such as: “How can you guide your loved ones to make the best decisions for you?”

Failure to complete end-of-life care planning often leads to unnecessary care and significant health care costs for tax-payers and families. Over half of Medicare expenditures are for health care provided in the last six months of life. The out-of-pocket expenses associated with this care often leads to bankruptcy. Health care debt is now the leading cause of bankruptcy.

Due to the recent Terry Schiavo case, End-of-Life Planning was an issue of considerable discussion in our Forums. Most disapproved of the government – particularly Congress and the President – becoming involved in private health care decisions. Group members expressed the need to publicize and offer assistance to all persons who had not engaged in conversations with their families about end-of-life care and those who had not completed durable powers of attorney.

### **Recommendation or Solution**

Create a new funding category under the Older Americans Act for Area Agencies on Aging (AAAs) for:

- End-of-life care outreach, education and benefits counseling;
- Increased assistance in completion of living medical durable powers of attorney.
- Integration of Person-Centered Advance Care Planning into AAA access and care navigation services.
- Working with health care institutions to promote Patient-Centered Advance Care Planning to ensure that all patients admitted to hospitals have advanced directives in their charts.
- Repeal the Patient Self-Determination Act, as the results do not justify the expense.

## **Planning Along the Lifespan SOCIAL SECURITY**

### **General Description**

Addressing Social Security was identified as one of the top priorities by those in attendance. Many expressed the need to address the long-term solvency of the Social Security System, but were skeptical that Personal Savings Accounts were a viable solution. The consensus was “if it ain’t broke, don’t fix it.”

### **Recommendation or Solution**

- Gradually increasing the age of eligibility to 70, use of a more conservative methodology for indexing of Cost of Living Adjustments; and

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- Increasing payroll taxes only if necessary.
- Don't privatize Social Security.
- Eliminate the base amount to be taxed. Whatever you make, you pay Social Security on.
- Phase in new retirement age of 70 over the next 30 years.
- Educate people to not depend on SS as sole source of retirement, explore other investment options, and start investing/saving at an early age.
- Increase the accountability of SS funds. Congress should not be able to borrow from the SS trust fund.
- Allow people to work and still draw SS.
- Eliminate any caps on amount of income generated before losing benefits.
- Increase base amount for taxation from \$90,000.

### **Planning Along the Lifespan LONG -TERM CARE**

#### **General Description**

Medicaid, a health insurance program for the indigent population, is the primary payer for all long term care. The Medicaid program is the nation's major public health insurance program and the primary public funding source of long-term care services for over 13 million older adults and people with disabilities. Medicaid revenue consists of both state and federal funding. Medicaid is the fastest growing expenditure in most state budgets. Medicaid long-term care services account for more than 40% of all national long-term care expenditures and 60% of all nursing home expenditures.

Medicaid long-term care expenditures are still predominantly targeted to institutional care, despite a 2000 study by the Assistant Secretary for Planning and Evaluation at the US Department of Health and Human Services which found that Medicaid could provide home and community-based services to five individuals for the same cost as nursing home care to one individual.

Medicare provides limited short-term funding for long-term care. The long-term care delivery system in the United States was developed to treat infectious communicable diseases and address acute health care conditions and is therefore not organized to address the chronic diseases of an aging society. The need for treatment and support of persons with chronic conditions will continue to grow and bankrupt individuals and governments unless reforms in financing mechanisms are made.

Americans prefer to remain in their own homes and communities, but current Medicaid policy still requires "special permission" for care at home, leading states to request a waiver of Medicaid requirements in order to provide home and community-based services.

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### **Recommendation or Solution**

- Develop a system of care that provides consumers access to services in a home or community environment first, eliminating the need for special “waivers.”
- Act on the Olmstead court decision by facilitating consumers’ access to the most appropriate services in the least restrictive environment, and the commitment made by the President in the “New Freedom Initiative” to rebalance Medicaid long-term care primarily through the expanded availability of home and community-based services.
- Offer incentives to companies to provide long-term care insurance to their employees;
- Make all premiums that individuals pay for long-term care insurance 100% tax deductible; and
- Expand Medicare to cover long-term care insurance, thereby spreading the risk, reducing the costs and preventing cost-shifting.

### **Planning Along the Lifespan PREVENTATIVE CARE**

#### **General Description**

Due primarily to an increase in chronic conditions, comorbidity and medical advances there are a growing number of older persons with functional limitations and increases in longevity. Recent “evidence-based” research demonstrates that health promotion and disease prevention not only contribute significantly to an individual’s quality of life, but also are a cost-effective means of reducing acute or chronic care costs.

Many of the disabling chronic illnesses which cause death or make it difficult for seniors to live independently with dignity in the community are preventable. For example, the incidence and severity of heart disease and cancer can be reduced by behavioral changes such as: (1) reducing smoking, (2) getting more exercise, and (3) improving diets. It is much more cost-effective to make preventative interventions with individuals than it is to wait until an acute care episode that requires costly institutionalization has occurred. Yet this is how our health and human service delivery system is now designed.

#### **Recommendation or Solution**

- Authorize \$50 million of funding in Title III-D Health Promotion of the Older Americans Act, with \$10 million of the appropriation set aside to pilot community-based efforts through the Area Agencies on Aging and local aging and healthcare providers to promote disease prevention services.
- Earmark a portion of this funding for a risk management approach which identifies individuals who are a high risk for institutionalization and provide enhanced preventive care and care navigation services.

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- Increase funding for senior wellness programs as well as Medicare preventive health coverage, to promote healthy aging and reduce future disease-related costs.

### **Planning Along the Lifespan PROTECTION OF FINANCIAL ASSETS & FINANCIAL LITERACY THROUGHOUT THE LIFE CYCLE**

#### **General Description**

Expenses for health and long-term care and retirement will grow as people live longer. It will be difficult for the government alone to meet these needs. Other options will be needed to finance these needs.

Very few Americans save enough money for retirement. Promoting financial literacy to assist Americans in learning to start saving early and to manage assets to last longer through longer retirements: planning for long-term living is needed.

#### **Recommendation or Solution**

- Increase knowledge of living wills/directives to physicians through healthcare providers and hospitals.
- Control health care costs/drug costs:
  - a. Reopen borders to purchase drugs from Canada and other countries that have the same FDA requirements as USA.
  - b. Review length of drug patents to allow potential for generic drugs.
  - c. Educate consumers and enlist support of MD on availability of drugs and provide information regarding cost comparisons and alternative therapy and treatments.
- Caution consumers to read the fine print on long-term insurance policies.
- Provide income tax incentives for home care.
- Educate throughout the developmental life span:
  - a. Provide after-school programs to elementary school students.
  - b. Provide core day electives and after-school programs for middle school students.
  - c. Provide core day electives to high school students.
  - d. Provide young adults more intense programs, using financial planners to show all options and possibilities for financial competence.
  - e. Provide college students classes on financial planning; decrease college tuition to parents who are still saving; and educate on life insurance.

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- f. Involve the full range of resources to provide literacy training:
  - 1) Offer grants to elementary schools for after-school programs.
  - 2) Provide grants, free curriculum and support to 4-H Clubs and Boy Scouts which would provide education to middle and high school students.
  - 3) Offer educational classes and grants to employers to reach out to the young adults in their work force.
  - 4) Increase retirement credits to support tuition payments of the middle-age students.
  - 5) Increased limits on child tax credits.
  - 6) Increase knowledge of life insurance as a savings resource.
  - 7) Require financial literacy education for parents who are in work force training.
  - 8) Provide tax credits to employers who give financial planning to their employees.
  - 9) Encourage community members to volunteer to conduct financial literacy classes.

### **Planning Along the Lifespan FINANCIAL FRAUD, ABUSE, EXPLOITATION**

#### **General Description**

Too many older Americans are victims of financial fraud, abuse and exploitation. Freedom from financial fraud, abuse and exploitation is integral part of elder financial security.

#### **Recommendation or Solution**

- Establish national abuse prevention education programs:
  - a. Work with faith-based groups.
  - b. Enlist service organizations and clubs.
  - c. Involve neighborhood work groups.
- Establish national hotline services to prevent fraud.
- Develop national clearinghouse for elderly services:
  - a. Those who need services.
  - b. Those who can provide services.
  - c. Background checks.
- Set up media coverage through television and national campaigns.
- Provide funding to encourage closer work with police departments and other law enforcement agencies.
- Expand the Older Americans Act Ombudsman program to provide advocacy for assisted living and in-home service consumers.

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### **Planning Along the Lifespan ECONOMIC INCENTIVES TO INCREASE RETIREMENT SAVINGS**

#### **General Description**

National economic incentives are needed to increase retirement savings. These incentives will need to focus on individual savings and employer-based pension programs.

#### **Recommendation or Solution**

- Set up income tax deductions for 401-K paired with simplified employer management of plans.
- Remove tax on interest earnings on savings.
- Provide a full tax deduction for long-term care insurance (no age requirement)
- Make people aware through educational programs.
- Increase access to educational resources.
- Incorporate as many real life situations as possible in educational programs.
- Provide incentives to corporations to encourage provision of pre-tax health insurance and long-term care insurance.
- Simplify the administration and record-keeping of employers' plans.
- Provide incentives for benefits to part-time workers.
- Do more to ensure accountability and forced savings.

### **Our Community CAREGIVER SUPPORT**

#### **General Description**

Research has shown that 5.8 - 7 million people (family, friends and neighbors) provide care to persons aged 65 or older who need assistance with everyday activities. These caregivers spend an average of 20 hours per week providing care. The majority of caregivers provide unpaid assistance for one to four years, often with no outside assistance whatsoever. As a result of their caregiving, informal caregivers often suffer financial loss and health complications. There is a growing need for respite, training, and financial support for caregivers. In many states, the program dollars and resources allotted for such services are so limited and/or stretched so thin, that they are increasingly unable to meet the needs of their respective communities. Waiting lists for some of these services may take as long as six months to one year before reaching consumers. In many cases, consumers' conditions have worsened and/or resulted in death while waiting for their turn.

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### **Recommendation or Solution:**

- Allocate more funding through the Older Americans Act to state for Area Agencies on Aging to provide respite, training, and financial support for caregivers.
- Provide more options for caregivers and care recipients so that the resources and services that are already available do not collapse under the increasing demand for services.
- Increase awareness and provision of support services and benefits for caregivers in the workforce (i.e. paid leave, counseling etc.).
- Make reduction of consumers on waiting lists for community-based services state and nationwide a priority.
- Partnerships among medical and social service providers need to be developed so that family caregivers have better options to care for themselves and their loved ones.
- Medical care settings need to make use of community caregiver resources a priority for patients who are caregivers for diseases such as Alzheimer's.
- If no link to social supports and education is established early in the disease trajectory several outcomes of caregiving and family life can be expected:
  - a. Patient will not be able to participate in legal and financial planning with spouse.
  - b. Family member will not seek help until they may be so burdened they cannot utilize help.
  - c. Health of caregiver will decline substantially as a result of chronic stress and insufficient social support.
- Family caregivers need a range of choices that relate to different approaches to coping, e.g.,
  - a. Services that support instrumental coping by correcting or doing something about the perceived problem.
  - b. Services that support coping by changing the beliefs or expectations of caregivers and the negative self-appraisal they experience from points of isolation and separation from social support.
  - c. Counseling, education and training can all help caregivers cope by changing their thoughts and beliefs about things that cannot be changed.

## **Our Community HOME AND COMMUNITY BASED CARE**

### **General Description**

There is an increasing preference among older adults and families to receive services in the community rather than in long-term care institutions. While there may always be a need for long-term care facilities for many isolated individuals who require around-the-clock care, ample research has demonstrated that long-term care can be provided in the community at a cost equal to or less than in a nursing home. Evidence also suggests that

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older adults and persons with disabilities are happier when they receive long-term services and supports in the community rather than in an institution. In many states there is a significant waiting list for community services while nursing homes have excess bed capacity.

Despite this evidence, the majority of federal and state funding for long-term care is spent on institutional care. It appears that federal laws make it much easier to spend funding to provide care in institutions rather than in their community. It also appears that special interests may also be keeping these barriers in place.

### **Recommendation or Solution**

- Federal laws should be passed which make it easier to spend Medicaid dollars for community-based services and supports without having to complete cumbersome waiver requests; and
- In the absence of passage of such laws, the Center for Medicare and Medicaid Services must streamline the approval process for waivers and the consolidation of waivers.

## **Our Community NETWORKING**

### **General Description**

Due primarily to a plethora of programs, funding sources, entrenched service providers and interest groups, tedious rules, regulations, and eligibility requirements, the service delivery system for older persons remains fragmented, difficult to access and confusing for older consumers. Despite some efforts to consolidate state and federally funded services at the state level, state and federally funded services at the local level are still fragmented because organizations are not willing to share consumer information and coordinate services. This results in consumers having to complete multiple applications for services and being sent repeatedly to organizations which they have already contacted about services. Consumers are routinely sent on “wild goose chases” and never receive the services they need because there is no efficient system for tracking consumers and sharing information (with their consent).

### **Recommendation or Solution**

- State and federal governments should mandate horizontal integration on the local level which includes the use of secure web-based information systems which protect the confidentiality of consumers, reduce duplication, improve access and alleviate the confusion of older consumers; and
- Financial incentives should be provided to communities to develop horizontally integrated service delivery networks.

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### **Our Community SENIOR CENTERS**

#### **General Description**

Older adults in the future will be better educated and will continue to work longer. They will feel better about their health, will be more health-conscious, but will still face health risks. They will be more diverse. Women will continue to live longer and alone. Men will narrow the gap with women and will more likely live with a spouse. Baby boomers have a broader range of interests than the current 65-70 year olds, but many of their interests involve passive entertainment. They have high interest in travel, computers, physical fitness, and adult education offerings. They have low interest in volunteering, games or participation in “childish” senior center activities. Boomers will likely want to meet new people, learn new things, participate in new activities and have access to the latest in technology. They want a modern, well-maintained, and interesting senior center location. Boomers seem to have little interest in belonging to any organization. They are well educated and are mobile.

Senior centers must also be aware of a dwindling interest on the part of prospects to belong to any organization. While this does not mean senior centers will become obsolete, it suggests senior centers have to re-think how they do business. They may need to be more open to offerings that do not take place at the center. Many baby boomers tell of concerns about getting to a center, or a center not being located near their residence. You might say that convenience is a high concern of boomers. Baby boomers also may not want to “join” a senior center, but may prefer attending specific events that interest them.

#### **Recommendation or Solution**

- Senior Centers will need to provide more education, adventurous, and short-term activities.
- In some cases, and given scarce resources, a center may need to make hard choices about whom they should attract and what will interest that target population; and
- Operating hours of senior centers will need to change. Instead of a lunch program, senior centers may need to offer evening meals. Centers will need to be open later in the day and on weekends and provide a wider range of services.

### **Our Community “ONE STOP SHOPPING”**

#### **General Description**

Due to differences in eligibility requirements and differences in necessary documentation required by all the separate state and federal programs, older persons are required to

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travel from place to place in order to receive all the services they need to survive and thrive. These are the very consumers who often have difficulty traveling at all. Coupled with the fact that older persons often have difficulty understanding the excessive paperwork they are required to fill out, this results in consumers who are not getting the services they need, and to which they are entitled.

### **Recommendation or Solution**

Agencies at all levels should be mandated to collaborate and implement a single point of entry where consumers may apply for all programs for which they are eligible. This would reduce duplication, allowing the client to give their information only once and alleviate the confusion and frustration experienced by these consumers. This would ease the strain of traveling to multiple places to apply, as well as the frustration of having to complete confusing paperwork over and over again. This move to improve access to services for the older consumers should be initiated at the state and federal level. Seniors need workers to help them find services they need, not only one service, but all that are needed. "One Stop Shops" and care navigators are needed.

## **Health and Long Term Living ALZHEIMER'S DISEASE**

### **General Description**

As more and more people age, more and more people will have a risk of having Alzheimer's disease. The need for expedient research is overdue. The rapidly increasing impact of Alzheimer's disease on long-term care is already quite evident. Community-based services here already have incomprehensibly long waiting lists. Texas is one of the three states which will have the largest increase in numbers of people diagnosed with Alzheimer's. By 2025 this state will have 470,000 people with the disease. This represents a 75% increase from 2000. Both Hispanics and African-American cultures have a higher risk of developing Alzheimer's disease. New research is finding that Hispanics develop Alzheimer's disease seven years earlier than Caucasians. Both African-Americans and Hispanics are diagnosed much later in the disease progression than Caucasians. This is not to say that the disease is generally diagnosed very early in Caucasians, as they are another significant section of the aging population.

Texas' rich diversity paired with its many excellent college and university settings would provide excellent resources for research on Alzheimer's disease to be done in the state. Concomitantly, more culturally diverse families could be involved in that research. Social and psychological research studies are needed to support adaptation and personhood of persons with the disease and family caregivers. Education, training and counseling strategies more culturally/ethnically suited to the requirements of persons and families need to be implemented from an evidenced-based research perspective. Texas needs to aggressively seek more research dollars. Outside the few university-based

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research sites, few opportunities exist for families in this state. Texas would be an excellent location for research involving the African-American and Hispanic cultures.

### **Recommendation or Solution**

- Develop more university-based Alzheimer's disease research centers in Texas to address the state's increasing disease prevalence.
- Develop research centers which look at cultural barriers to disease identification, caregiver burden and service utilization within the state's rich cultural diversity; and
- Develop other long-term care and cost-efficient options for families to utilize through the long trajectory of Alzheimer's disease.