CMS Long-Term Care Initiative

Helping American Families Find and Pay for Quality Long-Term Care

Among life's encounters, few are as burdensome as long-term care (LTC). For most families, the questions are daunting: where can we find reliable information about LTC choices?; what is the quality of providers?; and, how do we pay the huge costs?

Federal and State Medicaid spending for LTC is estimated to reach \$103 billion in FY 2004, with \$53 billion spent in nursing home care. Medicare spending on LTC services will be approximately \$25 billion in FY2004. Federal and State governments pay roughly 63 percent of all LTC expenditures; those needing care and their families pay out-of-pocket for 24 percent of all expenditures. The significant cost of unpaid care by family caregivers is not included in these figures.

Few families can afford the \$50,000 to \$100,000 in annual costs of nursing home care or assisted living and home care alternatives that average \$20,000 to \$30,000 per year. Thus, Medicaid spend-down becomes the alternative for many.

There are at least four groups of people seeking information and assistance on LTC:

- Those who are older who need care, for themselves or a spouse;
- Those who are middle aged through their 60's planning for retirement and need LTC insurance;
- Caregivers-whose spouse or parents suddenly need LTC; and
- Those who are younger or middle-aged, due to long-standing disability, catastrophic illness or accident.

Solutions—public and private sector—for all these groups are being discussed and debated, and many require legislation at either the federal or state level and may be years in development. This Long-Term Care Initiative begins with a program that can be implemented now.

CMS Education and Information-LTC Clearinghouse

The most basic need for most consumers is good, reliable information about available choices—including quality of providers and financing options—as well as referral to resources, agencies and services—the kind of function Medicare's 1-800 line already provides for other services.

CMS, as one of the most trusted information sources for seniors, will expand our information services to include additional LTC information and financing options. CMS will expand the scope of 1-800-MEDICARE and Medicare.gov to provide information on LTC choices and financing options.

Beyond basic information, consumers also need navigational tools, and referral to trustworthy resources and organizations. The consumer research that CMS conducted a little over a year ago, points to the need for "one place" where consumers can go that brings together financial, legal, housing/residential, personal, and community considerations.

As part of the LTC Initiative, the CMS State Health Insurance Assistance Programs (SHIPs) and the Administration on Aging (AoA) Aging and Disability Resource Centers will provide counseling on planning for LTC costs, insurance options, and other financial approaches. The Administration on Aging (AoA) and CMS awarded 12 state agencies grants to establish "one stop shop" centers as part of the local level LTC Partnerships. While Texas was not one of the grantees, the Texas Health Information, Counseling and Advocacy Program (HICAP) is committed to educating counselors, consumers, and caregivers about LTC and the need for advance long-term care planning.

HICAP Implementation of the CMS Long-Term Care Initiative

Lead staff from the Texas Department on Aging (now the Texas Department of Aging and Disability Services (DADS) and staff from the Texas Department of Insurance (TDI) participated in mandatory training on the LTC Initiative in the winter of 2003. In March 2004, HICAP presented a two-day training on topics related to LTC.

The current workshop series on the LTC Initiative is funded through a supplemental grant from CMS. The objectives of the workshops are to increase

local provider awareness of the CMS Long-Term Care Initiative, and to specialize HICAP certified benefits counselors as "Long-Term Care Counselors."

The CMS Clearinghouse, although still under construction, may result in referrals to the SHIP network.

Long-Term Care Clearinghouse Implementation

The majority of consumers are not aware of the choices available for privately financing for LTC coverage. The LTC Clearinghouse will target persons over 62 years of age utilizing a 1-800 service number and a web site to provide information on LTC insurance and related LTC financing information. The clearinghouse will address four basic elements: consumer research, clearinghouse content, web-based LTC Initiative decision tool, and an LTC Initiative call center. For the most part, individuals who contact the clearinghouse are referred to other sources of assistance and service.

Consumer Research

Consumer research will be conducted to develop promotion and content strategies. Consumer testing will also be conducted on the website and other information products to ensure the information provided by the clearinghouse is desirable, useful, and understandable.

Content Development

A two-track approach to content for the clearinghouse is necessary, focusing on the compilation and development of information. Internal resources have been used to identify and gather relevant sources of existing information on these topics, both inside and outside of CMS. Future efforts will include developing additional cleared language and consistent explanatory text for a variety of materials that will cross information channels.

The HICAP supplemental grant was used to edit the CMS National Training Manual to include Texas information and related rules regarding various LTC options. The manual also includes a state level list of resources and demographic information.

Website Development

On January 22, 2004, CMS launched a new "Long-Term Care" link on the www.medicare.gov web site. The site provides consumers with educational information and other resources designed to facilitate LTC planning and to make them aware of the choices available for private financing for LTC coverage. In addition to directing the consumer to the spectrum of supports and services

essential to a complete picture of planning for their LTC needs, the new information also incorporates an interactive decision-support tool, the Long-Term Care Counselor (LTCC). This component which is still under development has been renamed as a "LTC Planner." There is already a Long-Term Care link on the Medicare web site. Additionally consumers visiting the LTC page are offered an option to visit a Care Planner organization that walks an individual through a series of questions (a decision-tree) and creates a personalized report. The tool is intended to aid the consumer in considering their own personal risk for needing LTC and their ability to finance their projected needs in conjunction with other lifestyle choices. Based on the individual's response to the questionnaire, this tool will provide a personalized report to assist the consumer in the LTC planning process. According to the Medicare website, the LTC Planner will be available in March 2005. In addition to the information currently available, the LTC Planner will also include a calculator and a link to local resources.

Call Center Development

Call Center script content for the desktop has been developed and updated for persons counseling at the 1-800-MEDICARE number. The Training Team has covered the script changes during the weekly refresher training sessions. The Team will also make modifications to the training document for the next update release. CMS has not informed the SHIP network as to when their awareness campaign will kick off. It is however likely that 1-800-MEDICARE counselors are currently making referrals to local SHIPS, particularly given that the Long-Term Care link is available on the Medicare homepage.

Partnerships for Community-Based Education and Outreach

Important to the success of the clearinghouse is a community-based education and outreach effort designed to heighten awareness of the clearinghouse and provide a point of assistance to individuals seeking more detailed help with their particular life circumstances. The clearinghouse will need to refer individuals with more complex situations for help and assistance to SHIPs, the Aging and Disability Resource Centers, and the Area Agencies on Aging. Training is also an essential element to ensure partners have consistent, accurate, relevant, understandable, and current information.

Referral Sources & Support

As counselors, it is important to remember that you have a fundamental understanding of LTC financing options. While Texas HICAP does not expect LTC Counselors to be experts on every LTC financing option, HICAP does expect each counselor to be able to provide seniors and caregivers with the necessary information to make informed decisions.

As part of that counseling role, it is critical that counselors be able to determine when referrals to other trusted sources are necessary and appropriate. Please remember that the LTC Training Initiative is a partnership involving all HICAP partners. When appropriate, please refer matters to those trusted partners, including the Texas Department of Insurance, the Texas Department of Aging and Disability Services, and the Texas Legal Services Center/ Legal Hotline.