

Friday
11/20/98

10:00 - Mtg- **Rm 246** "Elderly Housing
& Long Term Care w/M. Deitch

11:00 - Mtg - ~~Rm 216~~¹⁰⁰ "w/Robert Reischauer,
Jeanne, Medicare comm.

12:00 - Mtg- **Rm 216** w/R. Tarplin, G. Claxton
J. Horvath

1:30 - Mtg- **Rm 216** w/Paul Kelly of Amer.
Dietetic Assoc

3:00 - Conf. Call w/Jim Tallon "Status of
Quality Forum" (**He will call Chris**)

4:30 - Mtg- **Rm 216** w/ Walter Moore of
Genentech

About Assisted Living

The NATIONAL CENTER FOR ASSISTED LIVING

Key Concepts Of Assisted Living

NCAL's General Philosophy

Definition

While assisted living is the most common term used in the nation, assisted living settings may be known by as many as 26 different names, including residential care, personal care, adult congregate care, boarding home and domiciliary care. Common to all these terms, however, is the understanding that an assisted living setting is:

- a congregate residential setting that provides or coordinates personal services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health-related services;
- designed to minimize the need to move;
- designed to accommodate individual residents' changing needs and preferences;
- designed to maximize residents' dignity, autonomy, privacy, independence, choice and safety; and
- designed to encourage family and community involvement.

Size

An assisted living residence is not defined by its capacity for residents, but by the scope of the services it provides. The size and configuration of each assisted living residence should be determined by consumer demand and the types of services provided. Services to individuals with mental illnesses, developmental disabilities, Alzheimer's disease, other forms of dementia or disabilities requiring specialized services, must be delivered in an appropriate and safe setting in compliance with state and federal regulations.

Physical Plant

An assisted living residence should be designed, operated, and maintained in a manner appropriate to the special needs of the population served. The residence should be located, constructed, and equipped in compliance with all applicable local codes and state and federal regulations. An assisted living setting should be designed in a way that maximizes the quality of life, independence, autonomy, safety, dignity, choice and privacy of residents. Settings should also be designed in a manner that encourages family and community involvement.

Move-In and Occupancy Agreements

New residents and/or their family members should receive an orientation about the services the assisted living residence offers.

Individuals should not be allowed to move into an assisted living residence that is unable to meet the full scope of their needs.

Occupancy agreements should clearly specify what services can and will be provided, the facility's rates for all services and payment structure, the facility's occupancy criteria, and relocation criteria.

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Service Agreements

When moving into an assisted living setting, each resident should be evaluated or assessed to determine how his or her need for services can best be met. A service agreement should be developed indicating what services will be delivered to meet particular needs based on the individual's physical, psychosocial and cognitive capabilities. The individual, family, or a responsible party should assist in the development of the service agreement, which should be reviewed and updated regularly or as needed.

An assisted living service coordinator should be designated to be responsible for developing, implementing, and evaluating the progress of the service agreement.

A copy of the agreement should be given to the resident or his or her legal guardian.

Health Needs

The assisted living residence should provide daily supervision or assistance with, activities of daily living and instrumental activities of daily living, coordinate services by outside agencies, and monitor the activities of the resident to ensure his or her health, safety, and well being. Daily assistance with activities may include the administration, supervision and/or assistance with self administration of medication by qualified staff person, and other health care services as permitted by state laws, rules and regulations.

An emphasis on wellness should be part of each setting's approach toward health care delivery. In addition, staff should assure that prompt and appropriate medical, health, and dental care services are obtained when required. The health care of each resident will be under the supervision of a physician of his/her choice.

Residents with temporary periods of incapacity due to major illness, injury, or recuperation from surgery should be allowed to remain in the facility or be readmitted from a hospital if appropriate services can be provided. If possible, the facility should help residents remain in the facility when death is imminent if appropriate palliative services can be provided in the setting.

Staff Qualifications and Training

The assisted living residence administrator should be responsible for the overall operation of the facility. The administrator should ensure that all staff members are qualified to care for residents and are competent in performing their duties consistent with applicable state and federal regulations. The administrator should assure that residents receive all services indicated in their service plan.

An assisted living residence administrator should have:

- An adequate education, demonstrated experience, and/or on-going training to meet the health and psychosocial needs of the resident; and
- Demonstrated management or administrative ability to maintain the overall operations of the setting.

A competent acting administrator should be designated to act on the administrator's behalf when the administrator is not readily available.

The personal care staff should:

- Be sufficient in numbers and qualifications to meet the 24-hour scheduled and unscheduled needs of residents and to deliver provided services; and
- Have adequate skills, education, experience and on-going training to serve residents and their families in a manner consistent with the philosophy of assisted living.

Personal care staff or medication assistants whose responsibilities include administration, assistance with self-administration or supervision of medications should be qualified by certification and/or training.

Staffing Patterns

Assisted living facilities should offer 24-hour protective supervision and oversight of residents. Assisted living residences should embrace the philosophy of "aging in place" which allows individuals to remain the residence as long as staff can properly provide for residents' health, safety and well being.

The number and type of staff employed by an assisted living facility should depend on a number of factors, including state regulations, the number of people living in the facility, each resident's service requirements, and the range of services offered.

The assisted living residence should employ adequate staff to maintain the facility in a manner that promotes the safety, health, and well-being of residents and staff.

Resident Rights

The philosophy of assisted living emphasizes the right of the individual to choose the setting for care and services. Resident rights should include the right to:

- Privacy
- Be treated at all times with dignity and respect
- Control personal finances
- Retain and have use of personal possessions
- Interact freely with others both within the assisted living residence and in the community
- Practice religion or abstain from religious practice
- Control receipt of health-related services
- Be free from abuse and neglect
- Organize resident councils

Upon move-in, all residents should be given a copy of their rights and responsibilities and should be encouraged to ask questions or discuss their rights with staff or the administrator at any time. A copy of those rights and responsibilities should be posted in a conspicuous place at all times.

Assisted living administrators should also:

- Permit access to the facility and to residents (with the individual resident's permission) by approved advocates and community organizations at reasonable times;
- Ensure that an informal or formal communications process is in place between the residence administration, residents and families;
- Establish residence rules governing visitors, usage of tobacco and alcohol and the use of personal property; and
- Ensure each resident is free from discrimination as provided by local, state and federal law.

Licensure and Certification

In most states assisted living residences are licensed or certified by an appropriate department or agency of the state that should have a process for issuance of initial licenses and for renewing existing licenses. Variance or waiver should be available to allow an individual facility to seek an exception to a requirement of the licensure or certification rules.

The state should maintain an aggressive program to seek out unlicensed or uncertified facilities and bring them into compliance with applicable licensure or certification standards. The health, safety, and well being of the residents should be the primary consideration when a state determines if a facility can be brought into compliance in a reasonable period of time or if closure is necessary. In addition, poor performing facilities that refuse to correct incidences of abuse and neglect should not be allowed to continue to operate.

Each state should also establish a program to reward -- through public recognition, incentive payments,

both -- assisted living residences that provide the highest quality care to residents.

Measuring and Improving Quality

The National Center for Assisted Living (NCAL) strongly believes that placing assisted living on a parallel regulatory track with nursing homes would be a mistake. Such a regulatory model would stifle the very spirit that led to the creation of assisted living. Instead of following the nursing home regulatory model, a quality assurance system for assisted living that focuses on customer satisfaction and actual outcomes should be designed and built. Such a system could be utilized by providers, consumers, managed care entities, and governments to ensure that quality services and care are being maintained. More important, such a system would better serve the interests of assisted living customers by providing them with powerful input into the quality evaluation process and the delivery of services.

Customer satisfaction measurement must be at the root of any system designed to measure quality in the assisted living setting. NCAL already has accomplished much in the area of customer satisfaction measurement in the assisted living setting. In 1996, NCAL, working with the Gallup Organization and the University of Wisconsin, conducted research and developed and tested a customer satisfaction assessment questionnaire based on those factors that residents deem important to their sense of satisfaction and well being.

Beyond customer satisfaction, any quality measurement system must also include measurement of actual facility performance. To be able to measure performance, certain data about each resident must be obtained, tracked and updated. From this data, quality indicators can be identified and utilized to track the outcomes of the care and services being provided by a facility. The quality indicators will produce tangible data and feedback that can be used to continuously improve assisted living quality. NCAL currently is conducting research and gathering data to develop quality indicators for the assisted living setting.

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About Assisted Living

The National Center for Assisted Living

Assisted Living Facility Profile

Number of Facilities-The absence of a common definition for assisted living makes it difficult to pinpoint the number of residences in the United States. However, recent analyses by NCAL indicate that there are approximately 28,000 assisted living residences housing 1.15 million people. NCAL's analyses of residences closely mirrors findings in a 1998 U.S. Department of Health and Human Services report on the assisted living industry.

Size-The average assisted living facility has 43 units and 40 residents. However, assisted living facility size varies greatly and facilities may be much smaller or larger.

Age of Structures-The average assisted living facility has been in operation for seven years and the physical structure that houses the assisted living residence has existed for 11 years.

Fees-Costs for assisted living residences vary greatly and depend on the size of units, services provided and location. Forty-nine percent of all assisted living facilities charge between \$1,001 and \$2,000 in average monthly rent and fees. Another 26 percent charge between \$2,001 and \$3,000 and 7 percent charge more than \$3,000 each month. A full 18 percent charge less than \$1,000.

Rules-A majority of residences (65 percent) allowed the use of tobacco and (52 percent) the consumption of alcohol. Consistent with the varying policies found in apartment living, 49 percent of residences allowed residents to keep small pets. Another 40 percent provided facility-owned pets for all residents to enjoy. A full 89 percent of assisted living residents need or accept help with housework, while 80 percent needed or accepted help with their daily medication.

Visitors-Most residences place no restrictions on visitors during the day, while 54 percent of facilities allow residents to have overnight guests.

Services-Assisted living residences typically provide or coordinate:

- 24-hour supervision;
- Three meals a day plus snacks in a group dining room; and
- A range of services that promote resident quality of life and independence, including:
 - Personal care services (help with eating, bathing, dressing, toileting, etc.);
 - Various health care services;
 - Social services;
 - Supervise persons with cognitive disabilities; Social and religious activities;
 - Exercise and educational activities;
 - Arrangements for transportation;
 - Laundry and linen service;

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- and Housekeeping and maintenance.

All information comes from the National Center for Assisted Living's (NCAL) 1998 nationwide survey of the assisted living industry or reflects NCAL's philosophy. To order a copy of the findings from the complete survey, call 1-800-321-0343 and request the 1998 edition of Facts and Trends: The Assisted Living Sourcebook.

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Assisted Living Resident Profile

Age-The "average" age of residents, women and men combined, is 83 years. The average age of the oldest residents is 97; the youngest is 64.

Sex-Nearly 3/4 of assisted living residents are female; 26 percent are male.

Typical Resident-The "typical" assisted living resident is an 83-year-old woman who is mobile, but needs assistance with one or two activities of daily living.

Number of Residents-Approximately 1.15 million people nationwide live in assisted living settings.

Activities of Daily Living-A full 26 percent of all residents need no help taking care of their activities of daily living (ADLs), others did in varying degrees. On average, assisted living residents needed help with 1.7 ADLs. The chart below details the various activities of daily living and the levels of assistance that assisted living residents need.

Personal Activities	Independent	Some Help	Dependent
Bathing	33%	47%	21%
Dressing	53%	32%	15%
Transferring	78%	13%	9%
Toileting	73%	17%	10%
Eating	87%	9%	4%

Other Common Services-A full 89 percent of assisted living residents need or accept help with housework, while 80 percent needed or accepted help with their daily medication.

Moving In-Residents come to assisted living facilities from a variety of settings, including:

- 58 percent moved from their homes
- 13 percent came from a nursing facility
- 12 percent came from another assisted living residence
- 12 percent came from hospitals
- 5 percent came from other settings

Moving Out-Conversely, as needs change, elderly people may relocate from assisted living residences. The NCAL survey found that a majority of residents left the assisted living facility because they needed a higher level of medical care.

- 43 percent went to a nursing facility
- 22 percent died
- 13 percent returned to their homes

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- 11 percent went to a hospital
- 9 percent went to another assisted living residence
- 3 percent went to other settings

Average Stay-Residents stay in assisted living residences an average of nearly 3 years.

Resident Rights-The National Center for Assisted Living advocates that residents' rights should include the right to:

- Privacy
- Be treated at all times with dignity and respect
- Control personal finances
- Retain and have use of personal possessions
- Interact freely with others both within the assisted living residence and in the community
- Freedom of religion
- Control receipt of health-related services
- Organize resident councils

All statistics come from the National Center for Assisted Living's 1998 nationwide survey of the assisted living industry. To order a copy of the findings from the complete survey, call 1-800-321-0343 and request the 1998 edition of Facts and Trends: The Assisted Living Sourcebook.

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Testimony of the National Center for Assisted Living Presented to the IOM Committee on Improving Quality in Long Term Care

March 12, 1998, Washington, D.C.

The National Center for Assisted Living (NCAL) appreciates the opportunity to testify today before the Institute of Medicine's Committee on Improving Quality in Long Term Care about quality in the assisted living setting. NCAL is the assisted living arm of the American Health Care Association and is a distinct organization that represents 1,600 non-profit and proprietary assisted living facilities across the country. NCAL is committed to fostering growth in assisted living and ensuring that people have access to quality assisted living services by supporting responsible public policies, providing professional education and development services, and by being an information resource for the public and media.

A Profile of Assisted Living

Based on a Scandinavian model for senior living, assisted living first emerged in America during the mid-1980s. The concept of assisted living is still new enough that the businesses that offer it and the states that license it do not agree on a precise definition or name for assisted living. Throughout the United States, assisted living is known by more than 25 different names. Some of the most common are "residential care," "personal care," "congregate care" and "board and care."

The absence of a common definition for assisted living makes it difficult to pinpoint the number of residences in the United States. Past studies put the range between 40,000 and 65,000 residences, housing up to one million people. However, recent analyses by NCAL indicate that the number of assisted living residences is probably closer to 25,000, and that there are approximately 800,000 people living in those residences.

Assisted living combines housing, personal services and light medical or nursing care in an environment that promotes maximum individual independence, privacy and choice. While assisted living residents may be too frail to live alone, they typically are too healthy to need most of the nursing services provided in a nursing facility. Assisted living residents share the risks and responsibilities for their daily activities and well-being with a residence staff geared toward helping them enjoy the freedom and independence of private living.

The Genesis of the Long Term Care Continuum

Not all that long ago, the long term care continuum essentially consisted of one service -- the nursing home. In the last 10 years we have seen a tremendous diversification of services with the rapid growth of assisted living, home care, and adult day care as consumers have sought services that precisely match their personal and health care needs. That diversification has meant that people have had more options from which to choose than in the past. It has also increased the ability of nursing homes to concentrate on caring for the oldest and sickest people in our society and to move into new areas such as subacute care. This evolution of long term care is continuing at a rapid pace.

The Assisted Living Philosophy

The philosophy of assisted living is to provide or arrange for supervision, assistance,

and limited health care services to relatively healthy senior citizens when needed. Residents can receive help with an array of personal activities, including: eating, dressing, bathing, transferring and toileting, as well as meal preparation, laundry, housekeeping, recreation and transportation. While assisted living residences usually do not provide 24-hour skilled nursing care, help with daily tasks may include the supervision or administration of medication by a qualified staff person. Frequently, health care services are delivered as part of a facility's "wellness program" for residents.

The philosophy also emphasizes the right of the individual to choose the setting for care and services. NCAL believes residents' rights should include the right to:

- Privacy
- Be treated at all times with dignity and respect
- Control personal finances
- Retain and have use of personal possessions
- Interact freely with others both within the home and in the community
- Practice religion or abstain from religious practice
- Control receipt of health-related services
- Be free from abuse and neglect

Assisted Living Services

Assisted living services can be provided in free-standing facilities, near to or integrated with skilled nursing facilities, as components of continuing care retirement communities, or at independent housing complexes. Residents typically can choose furnished or unfurnished studio or one-bedroom units with a private or semi-private bathroom. Living units can also be shared with another individual. Assisted living residences can range from a high-rise apartment building to a three-story home.

The number of units in assisted living residences varies widely as do the range of services that are offered. However, some generalizations can be made. Assisted living residences typically offer:

- 24-hour protective oversight and emergency response system
- Three meals a day plus snacks in a group dining room
- The provision and/or coordination of a range of services that promote resident quality of life, including:
 - Personal care, such as help with eating, bathing, dressing, and toileting
 - Limited health care
 - Provision and/or coordination of required social services
 - Supervision and oversight for persons with cognitive disabilities
 - Social and religious activities

- Exercise and educational activities
- Transportation
- Laundry and linen service
- Housekeeping and maintenance

The number and type of staff employed by assisted living residences varies greatly and depends on a number of factors, including state regulations, the number of people living in the residence and residents' service requirements. Assisted living residences employ staff members directly or contract for services with outside providers. A residence staff may include: personal care attendants, nurses, activities coordinators, food service managers, administrators and maintenance personnel. Contract services frequently include: podiatrists, nutritionists, physical therapists, beauticians and physicians.

Assisted Living Residents

The "typical" assisted living resident is an 82-year-old woman who is mobile, but needs assistance with one or two personal activities. Although most elderly assisted living residents are female, due to women's longer life expectancies, 29 percent are male. The "average" age of elderly residents, women and men combined, is 82 years according to a 1996 NCAL survey. NCAL would like to submit a copy of those survey findings for the official Committee meeting record.

That survey also found that while nearly one-third (31 percent) of all residents needed no help taking care of their own personal activities, others did in varying degrees. On average, assisted living residents needed help with 1.6 common personal activities. The table below provides additional details on the common activities with which assisted living residents need help.

Personal Activities	Independent	Some Help	Dependent
Bathing	34%	49%	17%
Dressing	58%	30%	12%
Transferring	78%	15%	7%
Toileting	84%	10%	6%
Eating	88%	8%	4%

NCAL's survey also found a full 65 percent of assisted living residents needed or accepted help with housework, while 49 percent needed or accepted help with their daily medication. Residents arrive from a variety of settings, according to the NCAL survey, with most residents moving to facilities from their homes. The following is a detailed list of where residents lived prior to moving into the assisted living setting:

- 59 percent moved from their homes
- 14 percent came from a nursing facility
- 11 percent came from another assisted living residence

- 11 percent came from hospitals
- 5 percent came from other settings

Conversely, as needs change, elderly people leave assisted living residences. The NCAL survey found that a majority of residents left their assisted living homes because they needed a higher level of medical care. The survey found that:

- 14 percent returned to their homes
- 45 percent went to a nursing facility
- 12 percent went to another assisted living residence
- 11 percent went to a hospital
- 16 percent died
- 3 percent went to other settings

Assisted Living Financing

Costs for assisted living residences vary greatly and depend on the size of units, services provided and location. NCAL's latest survey found that 52 percent of all assisted living facilities charge between \$1,001 and \$2,000 in average monthly rent and fees. Another 20 percent charge between \$2,001 and \$3,000 and 4 percent charge more than \$3,000 each month. A full 24 percent charge less than \$1,000, with less than 1 percent charging under \$500 per month.

About 90 percent of assisted living services are paid for with private funds, making the assisted living industry highly sensitive to economic forces. The Supplementary Security Income, Older Americans Act, and Social Services Block Grant programs pay for some assisted living services, while about 25 states allow the federal Medicaid program to pay for some service components. We fully anticipate Medicaid and other public programs will have a greater role in assisted living financing in coming years as the industry matures.

NCAL believes that people should have access to assisted living services regardless of whether they have the means to pay for the services themselves. To that end, NCAL supports public policies that allow people to have the resources necessary to access long term care services and the right to choose where they receive those services. NCAL also believes that states that opt to include assisted living as part of their Medicaid programs have a moral responsibility to ensure that they adequately support facilities at levels that ensure the delivery of quality services will not be jeopardized.

Other payers will also play a greater role in financing long term care in the future. Increasingly, assisted living is included as a covered benefit in long term care insurance policies. While managed care still plays a limited role in assisted living, there will be a greater reliance on assisted living to provide services to people covered by managed care plans that include long term care coverage. Currently, about 5 percent of assisted living residents pay for at least some of the services they receive through managed care programs according to NCAL's 1996 survey.

Government Oversight of Assisted Living

State governments regulate the assisted living industry primarily through licensure and certification laws. Assisted living regulations vary widely across the nation but

generally cover issues such as the physical setting, services, staffing, staff training, and resident admission criteria. Some states have very strict guidelines on who may live in an assisted living facility, while other states are more flexible and allow residents to "age in place" for longer periods of time. Without a doubt, there has been a marked increase in the volume of proposed assisted living laws and regulations as policymakers attempt to define and refine assisted living's role in meeting the long term care needs of a growing number of elderly.

Unfortunately, most states have approached the monitoring of quality in assisted living in the same way that they approach the regulation of nursing facilities -- that being a detailed, non-outcome oriented process-laden system. As the assisted living community has learned from the long nursing home experience, focusing on prescriptive requirements and annual inspections will never serve as a good measure of quality. A sporadic and detailed regulatory approach to measuring and ensuring quality is outdated and inherently lacks the focus that is needed on the individual assisted living resident and resident autonomy. That focus on the individual is the foundation of the assisted living philosophy. Indeed, it is consumers who have been driving the popularity of assisted living, not government programs, regulations or funding.

The Focus on the Individual

These factors are important to recognize if we are to create a system that promotes quality long term care services in the assisted living environment. As a whole, long term care is far more sophisticated than it was in 1987. Medical advancements, gerontological research and technological advancements have given providers powerful new tools, ideas and means for serving the elderly. Today, we have the knowledge and the technology to identify and track those resident characteristics that demonstrate whether quality services are being provided by a facility. This data, coupled with customer satisfaction survey results, can tell regulators, providers and consumers more about quality of care than any traditional survey checklist could ever provide. Why? Because good outcomes and customer satisfaction require a facility to actually deliver quality services rather than be good at going through the motions of delivering quality care and services.

One of assisted living's greatest strengths is its ability to constantly mold and shape itself to fit the needs of the individual customer. Regulations, by their very nature, are designed to achieve conformity and maintain the status quo. In some instances, such as fire safety codes, regulatory conformity is not only desired, but essential and should be maintained. We believe the potential consequences of failing to meet certain set standards are simply too dire to even consider measuring. However, in an industry that's designed to allow people to live as independently as possible the way they would live their lives in their own homes, it becomes apparent that a "one size fits all" approach to delivering services or regulating such an industry becomes difficult, if not impossible. Further, a regulatory environment that values strict regulatory conformity above individual choice and autonomy directly counters the very heart of the assisted living philosophy.

Ensuring Quality in Assisted Living

NCAL strongly believes placing assisted living on a parallel regulatory track with nursing homes would be a mistake. Such a regulatory model would stifle the very spirit that led to the creation of assisted living. Instead, a quality assurance system for assisted living that focuses on customer satisfaction and actual outcomes should be designed and built. Such a system could be utilized by providers, consumers and government to ensure that quality services and care are being maintained. More importantly, such a system would better serve the interests of the assisted living customer by providing him or her with powerful input into the quality evaluation

process and the delivery of services.

Customer Satisfaction

NCAL already has accomplished much in the area of customer satisfaction measurement in the assisted living setting. In 1996, NCAL, working with the Gallup Organization and the University of Wisconsin, conducted research and developed and tested a customer satisfaction assessment questionnaire. We would like to submit a copy of this questionnaire for the meeting record.

As part of our research and questionnaire development, we learned a great deal about what satisfies assisted living customers. Our research identified many key satisfiers in several areas such as management, resident's rights, facility structure, staffing, and assistance with transition upon moving into a residence. From our research we built a questionnaire designed to measure those factors that residents deem important to the sense of satisfaction and well being. Thousands of copies of that instrument have been distributed free of charge and are being used by assisted living facilities nationwide.

We believe that customer satisfaction measurement must be at the root of any system designed to measure quality in the assisted living setting.

Outcome Indicators

Beyond customer satisfaction, any quality measurement system must also include measurement of actual performance. To be able to measure performance, certain data about each resident must be obtained, tracked and updated. From this data, quality indicators can be identified and utilized to track the outcomes of the care and services being provided by a facility. The benefit to such an approach from a facility operations standpoint is that problems can be quickly identified and fixed. More importantly, a facility can use this data as part of its continuous quality improvement program. This data gives facilities the ability to measure their performance over a period of time and identify trends. Individual facility data could also be included in a network of data from facilities across the country which would facilities to see how their performance compares to other facilities in their community, state, or nationwide.

Development of Assisted Living Quality Indicators

The American Health Care Association already has created a system for nursing homes that utilizes such an approach. While outcome indicators for assisted living facilities will likely be very different than those used for nursing homes, the framework for developing such a measurement system has been designed, tested and implemented.

However, there will be challenges in developing an outcome measurement system for assisted living. First, we will need to identify that data -- those essential resident characteristics -- that should be tracked to develop quality indicators. Nursing homes were able to utilize the Minimum Data Set (MDS) as a basis for identifying clinical indicators. At present, there is no counterpart in the assisted living setting, although some research is being done in the area. In addition, the state of Maine has begun using a MDS instrument for assisted living. Another challenge is to develop quality indicators that are flexible enough to recognize the various levels of services that are being provided by assisted living facilities across the country. Regardless of these challenges to developing quality measures and indicators for the assisted living setting, NCAL is committed to working with the industry to see that such a tool for ensuring quality is developed and available for use.

A Model for the Future Regulation of Assisted Living

We believe that oversight of assisted living facilities, regardless of funding sources, belongs at the state level at this time. The industry is still relatively young and has not yet grown to its full potential. We also believe that the marketplace is the best guiding force for developing the industry. The assisted living landscape -- indeed the entire long term care continuum -- is in a stage of flux as managed care influences, the growing demand for long term care services and societal changes reshape the long term care world.

Given the fluid nature of long term care, states should retain the responsibility to set guidelines for assisted living facilities in areas such as physical plant, staffing and programming so that each state can craft a wide array of services that fit within their overall long term care plans and programs. In addition, we believe it is important for states to recognize that not all assisted living facilities are the same and that facilities serving special populations, such as people with Alzheimer's disease, need the ability to build and create living environments that differ from those that are designed to serve people without such conditions.

State Monitoring of Quality

Outcome indicators and customer satisfaction data have been proven to be powerful tools in assuring quality in long term care facilities. But they also have tremendous potential at the state level for monitoring quality in facilities. States should use these measures in lieu of traditional survey processes. Rather than focusing on annual checklist inspections, states would be able to attain regular reports about a facility's performance throughout the year. Further, the information that they would use to evaluate facilities will shed far more light on how a facility is performing than any state survey could hope to deliver.

We believe there is merit to the concept of separating the state's monitoring role into two distinct functions. The first role is one of monitor and advisor. In this capacity, the state would oversee the performance of facilities by monitoring outcome indicators and customer satisfaction data. When performance data indicate that a problem exists or may be developing, the state can work with the facility to precisely identify that problem and formulate a solution. The state's role as advisor would be to review facility plans to correct a problem and to make recommendations or share "best practices" guidance with facility staff. The common goal of both provider and regulator should be quality care and services. We believe that creating a structure that allows both regulator and provider to work together to achieve this common goal will help ensure consistent quality and benefit the assisted living resident. States should also explore incentives for their best performers to recognize excellence in the assisted living field.

Clearly, the state has a duty and responsibility to ensure the well-being of residents living in state licensed facilities. There are instances when the state does need a stick to ensure that a facility is living up to its responsibility to provide quality services. While such instances are likely to be rare, this second role of the state is one of enforcer. However, state regulatory staff responsible for enforcement should not be the same staff with advisory and monitoring responsibilities. It is important to avoid the commingling of these responsibilities if these two necessary functions are to operate in the manner in which they are intended. Despite these separate responsibilities, clear and open lines of communication are necessary if such a two-tiered system is to work efficiently and effectively.

Other Uses of Performance Measures

Another compelling reason to utilize outcome indicators and customer satisfaction for assisted living is managed care. Managed care is likely to rely more heavily on

assisted living in the future. Given this likelihood, it is logical to build a system that measures performance in terms that managed care can use. It continues to be very unlikely that any managed care entity is going to enter into a relationship with an assisted living facility simply because that facility did well on a state survey. Why? Because it is recognized that such a survey tells very little about how well a facility delivers care or how satisfied people are with a facility's services -- two vital concerns of managed care entities.

The Assisted Living Quality Coalition

As the Committee may be aware, a coalition of providers and consumers was formed in 1996 to work on the development of guidelines for state regulation of assisted living and to develop a system for ensuring quality in the assisted living environment. In addition to NCAL, the members of that Coalition include the American Seniors Housing Association, the American Association of Homes and Services for the Aging, the Assisted Living Federation of America, the Alzheimer's Association and the American Association of Retired Persons. As you can imagine, with such an eclectic group there have been some rather colorful discussions in the last two years. And while the Coalition continues its work, many of the concepts described in our testimony today are consistent with the approach that the Coalition is currently taking.

Recommendations to the Institute of Medicine

Per the Committee's request, NCAL offers the following recommendations:

- Recognize that assisted living is different from nursing facilities in design, purpose, and philosophy.
- Avoid "cookbook" regulations and enforcement structures that fail to recognize the needs of the individual and importance assisted living places on autonomy.
- Retain state responsibility for regulating assisted living regardless of payer source.
- Encourage the identification, support, and promotion of assisted living models that work.
- Recognize the need for regulatory and program flexibility for facilities that serve special populations such as persons with dementia or Alzheimer's.
- Recommend and support research in the development of quality indicators for use by assisted living facilities that take into consideration quality of life and hospitality factors.
- Support implementation of a national network of quality indicator data that can be used by providers, state governments and other parties to measure performance.
- Recommend that programs that are designed to serve the poor such as Medicaid be required to provide the resources necessary to deliver quality assisted living services.
- Support the education of physicians and other health care practitioners to build a broader understanding of how assisted living can meet the long term care needs of the elderly and other individuals.

NCAL appreciates the opportunity to testify today and will be pleased to provide the Institute of Medicine Committee on Improving Quality in Long Term Care with any assistance and information it needs as it continues its study.



HCFA prog mgmt → mandatory? paid for thru
mandatory offsets
room in discretionary
cap then

HEALTH CARE IDEAS

1. Long-Term Care. This initiative could be part of a “preparing for Medicare long-term reform” package; a women’s initiative if coupled with pension policies for women or family leave policies; or with an elderly housing initiative (policies to promote maintaining home ownership, beginning to promote assisted living facilities, and ensuring quality in nursing homes).

- **Long-term care tax credit.** (new policy) Along with the lack of coverage of prescription drugs, the poor coverage of long-term care represents a major cost burden for the elderly and their families. Long-term care costs account for nearly half of all out-of-pocket health expenditures for Medicare beneficiaries. This proposal would give people with three or more limitations in activities of daily living (ADL) or their caregivers a tax credit of up to \$1,000 to help pay for formal or informal long-term care. (Cost: About \$6 billion over 5 years).
- **Offering private long-term care insurance to Federal employees.** (new policy) Since expanding Federal programs alone cannot address the next century’s long-term care needs, the Federal government -- as the nation’s largest employer -- could serve as a model employer by promoting high-quality private long-term care insurance policies to its employees. Under this proposal, OPM would offer its employees the choice of buying differing types of policies and use its market leverage to extract better prices for these policies. There would be no Federal contribution for this coverage. (Cost: Small administrative costs; OPM estimates about 300,000 participants).
- **Family Caregiver Support Program.** (new policy) About 50 million people provide some type of long-term care to family and friends. Families who have a relative who develops long-term care needs often do not know how to provide such care and where to turn for help. This proposal would give grants from the Administration on Aging to states to provide for a “one-stop-shop” access point to assist families who care for elderly relatives with 2 or more ADL limitations and/or severe cognitive impairment. This assistance would include providing information, counseling, training and arranging for respite services for caregivers. (Cost: About \$500 -750 million over 5 years; discretionary).
- **Nursing home quality initiative.** (expanding on administrative initiative) On July 21, the President announced an initiative to toughen enforcement tools and strengthen Federal oversight of nursing home quality. On October 22nd, the Justice Department and HCFA held a conference to begin to develop other quality/anti-fraud and abuse initiatives with enforcement agencies from around the nation. Proposals to respond to these challenges and to implement the initiatives the President outlined in July can be included in the budget or as freestanding legislation. The initiative will no doubt include new enforcement provisions (e.g., increased penalties, etc.), as well as new funds to conduct more frequent surveys of repeat offenders and improve surveyor training. We are also working with DHHS and HUD to explore the possibility of establishing a Commission to

funded discretionary; user fee
included.

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budget

oversee HCFA's nursing home enforcement efforts as well as to begin to look at other types of housing where health care is offered (e.g., assisted living facilities). (Costs: \$500 - 750 million over 5 years).

2. Disability. This health initiative could be packaged with the non-health ideas such as the "Bridge" integration grant proposal and the access to information technologies initiative.

- **Jeffords-Kennedy Work Incentives Improvement Act.** (Congressional proposal; not passed in 1998) In the final budget negotiations this year, the Administration put the Jeffords-Kennedy bill on its list of priorities for passage. This bill would enable people with disabilities to go back to work by providing an option to buy into Medicaid and Medicare, as well as other pro-work initiatives. Although it was rejected by Republicans, the Administration has been stating that we will continue to fight to give people with disabilities the opportunity to work -- including the critical health insurance that makes work possible. (Cost: About \$1.2 billion over 5 years).
- **Tax credit for work-related impairment expenses for people with disabilities.** (new policy) Almost 75 percent of people with significant disabilities are unemployed; for many, the high costs of support services/devices, as well as the potential to lose Medicaid or Medicare coverage, prevent them from seeking and keeping jobs. This proposal would give a tax credit of \$1,000 to \$5,000 (depending on the design and costs) to people with disabilities who work, in recognition of their formal and informal costs associated with employment. This policy complements the Jeffords-Kennedy Work Incentive proposal, described above, but has the advantage of helping people in all states irrespective of whether states take up optional coverage. (Cost: Depends on the options; \$1 to 2 billion over 5 years).
- **Promoting Medicaid de-institutionalization.** One of the biggest frustrations for people with severe disabilities and their families is the "institutional bias" in Medicaid -- meaning the tendency to simply put people with great health care needs in nursing homes rather than develop viable, community-based alternatives. In 1998, HHS funded a small demonstration project in 4 states to test different models for offering people with disabilities the choice of care settings. This proposal would build on these tests by developing and propagating models that give people residing in a nursing home after a "date certain" a choice of care settings. (Cost: \$50 million over 5 years).
- **Medigap reform for people with disabilities.** In 1997, the President endorsed bipartisan legislation from Rockefeller, Chafee and Nancy Johnson that makes Medigap supplemental insurance more accessible to beneficiaries. The Balanced Budget Act did include some of its important protections for seniors on Medicare, but essentially excluded beneficiaries with disabilities from this reform. This proposal would make all Medigap insurers provide Medigap to people with disabilities when they sign up for Medicare. It would also ensure that they get a guaranteed issue Medigap option when in the event that their HMO withdraws from Medicare. (Cost: not clear that there will be costs).

*amplification
of HHS
request.*

3. Modernizing Medicare. These policies could “lay the groundwork” for the recommendations of the Medicare commission and re-affirm our ongoing commitment to improve and modernize Medicare.

- **Adopting private sector, competitive pricing strategies.** (FY 1998 budget) The President has consistently supported giving the Health Care Financing Administration the same tools to manage health care costs as are used by private sector plans. This includes competitive pricing for services like durable medical equipment and other supplies; expanding the competitive pricing demonstration for managed care; and adopting new payment methodologies like Centers of Excellence, among others. Although these ideas are being considered by the Medicare Commission, the President could take the lead on increased competition within Medicare since he has supported this approach in the past. (Savings: \$0.1 to \$0.5 billion, depending on the policies).
- **Reducing Medicare fraud and overpayment.** (Some FY 1999 policies; some new policies) Medicare fraud poses a serious threat to its financial well-being. In every budget for the last 5 years, the President has proposed new initiatives to help combat excessive payments and provider fraud in Medicare. Last year alone, Medicare saved over \$1 billion through these efforts. The President announced last January a 10-point plan for reducing fraud and overpayment, including provisions like reducing overpayments for drugs and ensuring Medicare does not pay for claims that ought to be paid by private insurers. HHS and the Department of Justice continue their efforts to enforce current policies and develop new ones. (Savings: From \$1 to 3 billion over 5 years, depending on the policies).
- **Protecting beneficiaries from HMO withdrawals from Medicare.** This year, a number of HMOs have pulled out of Medicare with only a few months notice, leaving 50,000 beneficiaries with no plan options in their areas. These withdrawals are causing beneficiaries unnecessary hardships as they rush to find alternative sources of coverage. The President has stated his determination to work with the Secretary of HHS and Congress to develop legislation to prevent this behavior in the future (e.g., limit the time between when a plan files to participate in Medicare and when enrollment begins, making it less necessary for plans to pull out at the last minute). (Cost: not clear that there will be costs).
- **Prescription drug coverage for Medicare beneficiaries.** (new policy) The lack of coverage for prescription drugs in Medicare is widely believed to be its most glaring shortcoming. Virtually every private health plan for the under-65 population has a drug benefit, in recognition of the medical community’s reliance on prescriptions for the provision of much of the care provided to Americans. Lack of Medicare coverage of drugs results in high out-of-pocket beneficiary costs -- which will only become larger in the next century since the vast majority of advances in health care interventions will be pharmacologically-based. Responding to this fact, Republicans and Democrats on the Medicare Commission, as well as almost every health care policy expert, are consistently stating that reforming Medicare without addressing the prescription drug coverage issue

would be a mistake. We are developing a wide variety of options, including a means-tested Medicaid option, a managed care benefit only approach, a traditional benefit for all beneficiaries, and an unsubsidized purchasing mechanism that uses Medicare's size as leverage for drug discounts for beneficiaries. If desirable, a proposal could be included in the budget or coordinated with the March release of the Medicare Commission's recommendations. (Cost: Varies significantly depending on proposal, ranging from \$1 to 20 billion a year).

- **Redesigning and increasing enrollment in Medicare's premium assistance program** (extension of July executive action and new policy). Over 3 million low-income Medicare beneficiaries are eligible but do not receive Medicaid coverage of their Medicare premiums and cost sharing. Many more may not get enough assistance through the new, BBA provision that is supposed to help higher income beneficiaries. We are developing a range of proposals that build on the President's actions in this area to better utilize Social Security Offices to educate beneficiaries about this program, to reduce administrative complexity for states and to give them incentives to engage in more aggressive outreach efforts. (Costs vary depending on policies; up to \$500 million over 5 years).
- **Cancer clinical trials demonstration** (FY 1999 budget; not passed). Less than three percent of cancer patients participate in clinical trials. Moreover, Americans over the age of 65 make up half of all cancer patients, and are 10 times more likely to get cancer than younger Americans. This proposed three-year demonstration, extremely popular with the cancer patient advocacy community, would cover the patient care costs associated with certain high-quality clinical trials. (Cost: \$750 million over 3 years).
- **Providing needed education funds to children's hospitals.** (new policy) Medicare has invested billions of dollars in graduate medical education to hospitals since 1966. However, because of its current formula, free-standing children's hospitals are forced to shoulder the majority of the cost of training pediatricians, placing them at a severe financial disadvantage. This proposal would consider additional funding outside of Medicare to provide reimbursement for the training costs incurred by children's hospitals. Addressing children's hospitals' education financing has bipartisan support, and Senator Frist has made this a priority for the Medicare Commission. (Costs: depends on the proposal). *which margins do they use?*

Don't do it like this one →

4. Health Insurance Coverage Expansions. The rising number of uninsured makes the need to propose insurance expansions important.

- **Small business purchasing cooperatives** (different version in previous budgets; not passed). Over a quarter of workers in firms with fewer than 10 employees lack health insurance — almost twice the nationwide average. This results in large part because administrative costs are higher and small businesses pay more for the same benefits as larger firms. This initiative encourages the development of purchasing groups modeled on FEHBP by allowing them to be considered non-profits (which will facilitate private

foundation support), providing Federal grant support, and having the Office of Personnel Management provide technical assistance. We are also considering giving employees who purchase coverage through the purchasing groups with tax credits to encourage them to take up coverage. (Cost: about \$50 to 100 million over 5 years).

- **Children's health insurance outreach** (FY 1999 budget; not passed and new policy). To date, 42 states have had their CHIP plans approved. These new expansions have great potential to help uninsured children, but not if families do not know or understand the need for insurance. Moreover, over 4 million uninsured children are eligible for Medicaid today. To facilitate spending on outreach, this proposal would allow states to draw down more of its CHIP allotment for outreach. An additional proposal is to pay for a nationwide toll-free number that connects families with state eligibility workers. NGA is sponsoring this line for one year only; such a line is essential for the nationwide media campaign that we are planning to launch in January with the NGA. (Cost: small but unknown at this point; could be funded through tobacco recoupment)
- **Demonstration of Medicare buy-in for people ages 55 to 65** (full proposal in FY 1999 budget; not passed). Americans ages 55 to 65 have a greater risk of becoming sick; have a weakened connection to work-based health insurance, and face high premiums in the individual insurance market. The latest report shows that the uninsured are growing at the fastest rate in this age group; by 2010, the number of uninsured people age 55 to 65 will nearly double. Building on last-year's proposal, we could allow a limited number of people ages 62 to 65 and displaced workers ages 55 to 65 to buy into Medicare. As a demonstration, this might gain the support that it lacked last year. (Cost: at least \$500 million over 5 years, which would assist about 30,000 people).

Public Health/Underserved Populations

- **Combating Resistance to Antibiotics (Super Bug).** Recent reports have indicated that resistance to antibiotics is increasingly becoming a public health crisis, causing prolonged illnesses and even death. For example, 500,000 Americans per year are infected with Staph (*Staphylococcus aureus*), a commonly-acquired, potentially lethal, hospital-based infection. The bacteria now only responds to vancomycin, and CDC has recently documented the first cases of resistance to this last resort drug. The hospital costs alone associated with treating antibiotic resistance total over \$600 million per year. This new initiative could address this critical emerging problem through: (1) a major health-warning outreach campaign involving hospitals, health professionals, and managed care organizations; (2) new research and surveillance efforts to understand where and why antibiotic resistance occurs and develop effective responses as well as to develop new vaccines that could help limit the occurrence of diseases where there is or will soon be increased antibiotic resistance; and (3) demonstrations that bring in a team of public health experts into a community to implement and test effective strategies to combat antibiotic resistance. (Cost: \$25 million per year). *When this prob gets solved, we can't take credit.* ATCPR?
- **Assuring Ability to Detect and Manage Bioterrorism.** Bioterrorism is becoming an increasing threat that has the potential to injure or kill millions of Americans through deadly diseases, such as anthrax. While law enforcement and intelligence agencies seek to thwart these kinds of attacks, when prevention fails, we need a system in place that is prepared to manage and minimize the public health consequences. Unfortunately, unlike many types of attacks, bioterrorist threats could go for days or even weeks without being detected as they could be noticed only when clusters of deaths or a series of illnesses begin to emerge. Therefore, it is critical that the nation's public health system is equipped to both detect and respond to this potential problem. This initiative would: train epidemic intelligence officers who can coordinate with state health departments and other intelligence officers to identify and respond to attacks; develop a Metropolitan Medical Response System, a mass casualty emergency response system, that includes primary care, emergency transportation, and decontamination abilities that will be critical to save lives in the event of an attack; create and maintain a stockpile of pharmaceuticals, that would be critical in the event of a bioterrorist attack that could expose hundreds of thousands of Americans to a disease (current stockpiles, that contain many inactive antibiotics, are inadequate to address a major outbreak); and improve research to develop new vaccines and antibiotics that could be used in the event of an attack. (Cost: \$100 to \$300 million per year).
- **Announcing a New Initiative to Prevent and Treat Asthma.** Over the past 15 years, there has yet to be a fully understood and greatly concerning increase in the number of children afflicted with asthma. In fact, cases have doubled to total about 15 million, with the increase in rates highest in children under 5 years old. This disease is one of the leading causes of school absenteeism, accounting for over 10

package together

What are health plans doing to solve this problem

Carol Browner

million missed school days. Recently, the National Heart, Lung, and Blood Institute developed new treatment guidelines designed for health care providers and patients with asthma. These guidelines demonstrate that appropriate medical care, along with measures to control allergens and other environmental triggers, can tremendously reduce the frequency and severity of attacks. The proposed initiative is designed to broadly disseminate these guidelines to State and local public health programs. These public health coalitions will then work with schools, child care organizations, businesses, and other community organizations to reduce harmful exposures to asthma patients and make it easier for asthma patients to follow their treatment plans. This initiative would complement our current efforts to identify and enroll eligible children in Medicaid and the new Children's Health Insurance Program. (Cost: \$50 million).

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- **Launching New Initiative to Improve Awareness and Treatment for People With Mental Illness.** Mrs. Gore's office is recommending a White House Conference on Mental Health for this spring to raise awareness about mental illness and to take the next steps to improving access to and treatment of mental health. In addition, next year, HHS will release a historic Surgeon General's report documenting the widespread incidence and impact of mental illness. To bolster these activities, the Vice President's office would like to unveil a series of public-private initiatives to further improve access to prevention and treatment and to raise awareness about mental health, including involving foundations, businesses, and states in new partnerships to highlight and build on cost effective coverage and delivery practices; and improving the delivery of mental health services in Federal health programs. We believe this initiative should also include increases in the mental health block grant which enables states to provide critical mental health services, including assuring homeless shelters identify and treat mental illnesses, improving the availability of state-of-the-art treatments, and providing new incentives to communities who have implemented effective mental health programs, including homeless programs that effectively address mental illness. (Cost: Up to \$100 million per year).

mental health K-DA landmark for CTCs

- **Applying Effective Prevention Strategies to Combat Heart Disease, the Nation's Leading Killer.** While diseases, such as cancer and HIV/AIDS receive far more media attention, heart disease is the leading killer of women and men across nearly all racial and ethnic groups. More than 960,000 Americans die of heart disease each year, accounting for more than 40 percent of all deaths, and 58 million Americans live with some form of this disease. This disease can be markedly reduced by: preventing smoking which causes one-fifth of all cardiovascular deaths; improving physical activity, as Americans who are not physically active are at twice the risk of heart disease; and improving nutrition. We are taking new strides in research in this area, and NIH recently launched one of the largest clinical prevention trials, that is examining heart disease among postmenopausal women, including the role of nutrition, increased exercise and physical activity. This initiative could also emphasize: launching a new partnership with aging networks to evaluate and

Dan likes this cut prevention block grants

National diabetes prog.

improve nutrition in public-private programs; measuring successful community prevention approaches and replicating them nationwide; and creating a network of, educators, churches, minority-based organizations to launch nationwide awareness campaign about prevention. (Cost: \$20 million per year supplemented by NIH funding in this area).

- **Improving Emergency Medical Services in Rural Areas.** The presence of viable EMS systems is critical for residents in rural and frontier areas. Because of the high rates of occupational injury associated with employment unique to rural areas, such as farming, mining, and fishing, rural residents experience disproportionate rates of trauma and medical emergencies. Although farmers constitute only 4 percent of U.S. workers, 38 percent of all machinery related deaths occur on farms. In addition, the death rate from accidental injuries in most rural areas is over twice the rate for the largest city. Long distances between hospitals, tertiary care centers, and other providers can increase the morbidity and mortality associated with medical emergencies. Financing modern emergency care systems in small rural communities is difficult at best. Many rural and frontier communities face challenges in obtaining ambulance equipment and communication systems and recruiting, training, and retaining EMS personnel. This proposal would provide funds to States and local communities to improve access to 911 services or alternative systems where the 911 option is not economically viable. It would also develop and fund programs to help rural communities train local citizens in CPR and first responder techniques, help recruit and retain EMS personnel, and develop distance learning programs for EMS staff in order to ensure they receive appropriate training and support. (Cost: \$50 million).
- **Investing in Promising Biomedical Research.** We are now poised to make revolutionary advances that could dramatically alter and improve the way we treat diseases. To help realize these new possibilities, the President's FY1999 budget included a historic multi-year investment in biomedical research and Congress funded NIH at even higher levels (a \$2 billion increase this year). However, there is no evidence that the Republicans in Congress have any intention of altering their longstanding commitment to outbid us on NIH funding. It appears futile to compete with them while still maintaining our own commitment in other priority areas. Moreover, even NIH is beginning to get a level of scrutiny about their ability to wisely and appropriately spend such large increases. Having said this, the research issue has captured the imagination of virtually every community, and the President and Vice President have both spoken at great detail about the importance of this type of investment. Therefore, it seems ill-advised not to continue some level of increased commitment. We recommend somewhere between \$500 million and \$1 billion, although the higher amount is only conceivable assuming we use at least some tobacco dollars in this area.
- **Improving Access to Promising HIV/AIDS Drugs.** With progress in lifesaving

ASMB
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it.
Dan
too.

HIV/AIDS therapies, the AIDS community has made it a top priority to extend these state-of-the-art treatments to Americans in need. While we have supported healthy increases in these areas, in some states, such as Texas and North Carolina, there are up to year-long waiting periods to get on these drugs, and other states have chosen to limit their programs so they do not pay for the comprehensive range of drugs needed to effectively treat HIV. Therefore, we are recommending new investments in the AIDS Drugs Assistance Program (ADAP) which helps people pay for these costly therapies that can run as high as \$15,000 per year. In addition, we believe we should propose new increases in prevention and treatment for HIV/AIDS. (Cost: approximately \$150 million per year).

- **Continuing the President's Successful Race and Health Initiative.** Minorities suffer as much as five times the rate for certain diseases and mortality rates, such as cancer, diabetes, heart disease, immunizations, HIV/AIDS, and infant mortality. In fact, infant mortality rates are 2½ times higher for African-Americans and 1½ times higher for Native Americans, and African-American men under 65 suffer from prostate cancer at nearly twice the rate of whites. The President's race and health initiative, designed to eliminate the startling racial health disparities in these six critical health areas has been extremely well received by the minority and public health communities. When launching this program last year, we committed to investing \$400 million over five years, and this budget should include no less than the \$80 million promised for each year. This initiative could fund: (1) new incentives to public health programs to target disparities, including creating incentives for communities to develop effective private-public cardiovascular outreach campaigns and developing new networks with managed care, minority-based organizations through the National Diabetes Education Program to implement treatment guidelines, (2) a \$30 million grant program to test innovative community approaches to addressing these disparities and replicating these programs nationwide; and (3) investments to build on this year's historic prevention and treatment efforts to address the ongoing health crisis of HIV/AIDS in the minority community. These investments could be supplemented by new efforts at NIH to better understand these disparities and develop new approaches to disseminate the most up-to-date information. (Cost: \$120 million - \$150 million per year).
- **Enhancing Drug Approvals, Food Safety, and other FDA priorities.** The FDA has unprecedented new challenges, including: a surge in promising technologies and drugs that need approval; increasingly challenging diseases, such as AIDS and emerging pathogens; important public health issues such as food and blood safety and dietary supplements; as well as major new statutory responsibilities from FDA reform. However, funding for this agency has not increased in several years. This has serious implications for the agency, as food inspections, organ banks, and drug companies are rarely inspected; and it is more challenging to meet drug approval needs. OMB and HHS have made it a high priority to increase funding for this agency this year, and the Vice President's office has recommended increases as well.

We are working closely with them to determine the most advisable and needed funding.

- **Improving Health for Medically Underserved Native Americans.** Native Americans have disproportionately high rates of chronic and acute diseases (as much as five times higher diabetes rates, and three to four times the rate for SIDS). It is widely recognized that the IHS, the main health care resource for Native Americans living on reservations, does not have sufficient funding to address the needs of this population, and OMB and HHS are proposing increases in this area. We believe that this initiative should also include an emphasis on health areas where there are particularly large disparities, such as diabetes and cancer. This would build on the President's efforts to elevate the Director of IHS to an Assistant Secretary position and his participation in the conference on "Building Economic Self-Determination in Indian Communities". It would compliment well his race and health initiative. (Cost: working with HHS and OMB to determine needed increases).
- **Improving Access to Emergency Room Care for Veterans.** As part of the President's request to bring Federal health programs into compliance with the patients' bill of rights, there is some question as to whether the VA provides veterans adequate access to emergency room services. The VA currently only pays costs associated with emergency services provided to veterans at VA hospitals; and some argue that even though this is a discretionary, deliberately limited program, it is not entirely consistent with the patient protection to assure emergency services when and where the need arises. We expect Senator Daschle will offer a proposal to extend veterans' access to emergency rooms at non-VA facilities, and it is advisable for us to address this widely-publicized issue to some extent so we are not perceived as renegeing on our commitment to apply the patients' bill of rights where we can. (Cost: VA's current proposal costs \$550 million per year. However, OMB has been working to dramatically reduce the costs of this proposal).
- **Investing in Promising DoD Breast Cancer/Prostate Cancer Research Programs.** We have continually highlighted DoD's innovative, popular cancer research programs (most recently the President announced grants in the DoD prostate cancer research program in his Father's Day radio address). However, we have been increasingly criticized by advocates who question the Administration's commitment to this program because the President's budget has never proposed any funding for this critical program. Advocates believe that the lack of an Administration proposal makes it much more difficult to lobby for funding on the Hill. DoD is somewhat resistant to this concept as they believe that although they have developed a model program in response to a Congressional mandate, cancer research is not within their military mission. If you chose to fund this area, we would need to at least match FY1999 funding and potentially increase this amount. (Cost: About \$250 million per year).

osteoporosis - stress fractures & ♀ recruits.

Bob
Kyle



DATE: 11/16

TO: Chris Jennings

TELEPHONE: _____ FAX: _____

FROM: Meredith Miller
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COMMENTS:
FVT - we are working on the
Campaign for a mid-December
kickoff and have been talking
to HHS to work as partners

NUMBER OF PAGES INCLUDING COVER SHEET 9



NOV 13 1998

MEMORANDUM FOR THE DEPUTY SECRETARY
CHIEF OF STAFF

FROM: Meredith Miller *MM*

SUBJECT: Health Education Campaign

A number of recent developments within and outside the Department have presented us with a prime opportunity to launch a Health Education Campaign within the next month. The imminent announcement of a health education campaign by the Employee Benefits Research Institute (EBRI) speaks to the urgency of launching our own Campaign on an accelerated timeframe, as discussed in more detail below.

We have already begun to lay a foundation for the Campaign. HHS has expressed a willingness to serve as a founding partner for the Campaign kickoff. In July of this year, we informally told stakeholders that the agency will be launching a Health Education Campaign to include possible partnerships with private sector entities. PWBA's FY2000 budget proposal includes a request for funds to support several components of the Campaign. Most recently, we met with Susan King to outline a preliminary action plan (Attachment A). The Campaign will also come on the heels of the ERISA Advisory Council's November 13th report to the Secretary recommending an expanded health education role for the Department.

Campaign message: The broad message of the Campaign could be that the Department has a unique role to play in the current flurry of health education activity taking place in the public and private sectors. First, it has a unique focus: employer-based health benefits. Second, the Department reaches out to a unique audience, i.e. key players that groups like EBRI are likely to overlook: consumers (with particular emphasis on vulnerable subgroups such as women, low wage workers, new entrants to the job market, dislocated workers and older workers), labor and small businesses. Third, the Department provides health education through a unique framework — by empowering workers with the information toolkit they need to navigate major life events that affect their health care needs, such as changes in job or marital status or onset of a serious illness. That toolkit would include both information about legal rights (a role that DOL already plays) and “value-based purchasing”, i.e. making health care decisions based on quality as well as cost.

Campaign products: The Campaign kickoff could include the announcement of two new tools for the toolkit: a “Top Ten” brochure of what workers need to know, modeled after our pension booklet of the same title; and a guide to protections that workers have when they face major life and work events that impact on their ability to get needed health care. (A similar factsheet was prepared for the upcoming Newborns Rollout Event — Attachment B). Other tools, e.g. an

Working for America's Workforce

expanded website, series of "life event"-specific pamphlets, and small business guides, would be developed at a later date (see Attachment A).

Impact of EBRI's current activities on timing of DOL Campaign: After learning about the Department's plans to launch a campaign, EBRI President Dallas Salisbury¹ approached us this summer regarding a potential partnership. Upon receiving a lukewarm response from us, he convened a kickoff meeting at the end of October. At that meeting, which was attended by PWBA staff, it was clear that he had the capability and intent to kick off his own "Consumer Health Education Campaign" (CHEC) in November or December 1998. EBRI appears to have the financial commitment of key ERISA industry groups as well as provider groups. (It is aiming for a three year budget \$1.5 million for three years with ten paying partners.) Although DOL and HHS were at the planning meeting, it is unlikely that EBRI's core partners will include government, consumer groups, labor or small business. CHEC's central message is also different than the type of message DOL is likely to convey, i.e. consumers need to be taught to change their behavior and recognize the importance of getting health care coverage.

Other DOL activities already underway that support the Campaign:

A health education campaign will serve as an efficient and effective complement to PWBA's customer service role and to our pension education campaign. In FY 1998, PWBA received over 155,000 calls, and of those, more than half pertained to health care. Effective health education at the front end can reduce the number of disputes and wrong decisions later on, and arm workers with the self-help tools they need to resolve problems that do arise without outside assistance.

We have expanded our website to link users to useful health information, but much more needs to be done to achieve the level of effort of other public and private sector entities. To quote a recent Wall Street Journal article on how to select health care, "[t]he amount of health care information available to consumers is exploding." Other leading newspapers and magazines have also recently given top billing to this issue. Our Office of Public Affairs has identified over 20,000 websites that provide this information. We plan to build more links to good consumer guides and other "tools" that have already written, as well as increase coordination with the vast health care websites of agencies such as HCFA and OPM.

PWBA's Office of Public Affairs has been disseminating health care information through written materials and PSAs for several years (Attachment A), including booklets about new changes in the law, retiree health and dislocated workers. In addition, we are expanding our "ELAWS", our interactive, Internet-based source of guidance to employers and employees about legal requirements.

¹By way of background, when the Department launched the Retirement Savings Education Campaign in 1995, we established initial partnerships with 65 public and private sector entities. We collaborated with EBRI to bring in the private sector. After the Campaign was launched, EBRI established a separate nonprofit arm called the American Savings Education Council (ASEC). To date, ASEC has over 250 members.

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Recently, we have begun exploring additional partners for our health education efforts in addition to HHS. We met with the Service Workers International Union regarding possible focus groups that would provide a greater understanding of the types of health care information that workers and plan sponsors need. To reach out to the employer community, we met with the Washington Business Group on Health to discuss that sector's growing interest in the link between providing good health care to the workforce and increased productivity. Other possible federal agency partners include the Small Business Administration and Treasury.

Other related activities outside of DOL:

The work of the President's Quality Commission and follow up Commission activities currently underway bear direct relevance to PWBA's health education efforts. The **Bill of Rights** included recommendations on disclosure of information to workers about health care quality and coverage. The Commission's **final report** focused on voluntary market forces as a tool for quality improvement, and included recommendations for improving the methods used for measuring and reporting information on health care quality and arming consumers with more comparative health care information.

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The Department is participating in two entities that are outgrowths of the Commission work that address the health information needs of consumers. The Quality Interagency Coordination Task Force ("QUIC"), which convenes federal agencies involved in health care, has two work groups that are looking at health education, i.e. consumer information and quality measurement. All the work groups will be reporting to QUIC Co-Chairs Herman and Shalala on January 13, 1999. The Department has also been a member of the planning group for the private sector Forum on Quality Measurement and Reporting that will work to improve the coordination of existing voluntary efforts to measure plan and provider quality² and their responsiveness to the needs of

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employers, workers, and other information users.

Recommendations

The above activities strongly suggest two reasons for moving quickly ahead to initiate a Health Education Campaign that emphasizes the importance of being a well informed health care consumer and being prepared for major life events that change one's health care needs. First, the Campaign appears to serve as an excellent complement to and natural hub for the Department's ongoing health education efforts. Second, the Campaign provides us with a useful vehicle for quickly stepping up our level of effort so that we are perceived as yet again a leader like we were in the pension education campaign among the many public and private sector groups who are already actively at work in this area, while ensuring that all key groups are adequately represented. Finally, we believe that there is considerable support for the Campaign among the public, private and nonprofit sectors.

Attachments (Attachment A - Action Plan; Attachment B - Newborns Rollout Life Event Memo)

DOL Health Education Campaign

Need

- Workers go through many life changes that affect their health care coverage and should have sufficient knowledge to make informed decisions.
- Many are uninformed about their new rights and their responsibilities. PWBA responds to over 80,000 inquiries each year from participants and plan sponsors about their employer provided health benefits.
- The Department is in a unique role to lead this education effort since we regulate employer provided health plans. The Department can also rely on the experience and expertise we have accumulated from our successful retirement savings education campaign.

Message

- For workers:
 - Education is good for your health. Know your rights. Empower yourself with knowledge about your benefits.
- For employers:
 - Health benefits for workers makes good business sense especially for small businesses. Health benefits gives these employers a competitive advantage to attract qualified employees.

Theme of Campaign

- For workers:
 - Be prepared for those life phases or work events that affect your health care needs:
 - Changes in employment status to include new hire, job transition, family leave, & retirement.
 - Changes in family status to include marriage, having a baby, adoption, divorce, death of a spouse.
- For employers:
 - Making the right choices in selecting health benefits for their workers and their business.

Targeted Population

- All Users of Job-Based Health Insurance, particularly those most at risk:
 - low-wage workers
 - women
 - young workers just entering the job market
 - dislocated workers/persons changing or between jobs
 - older workers
- Employers/Plan Sponsors, particularly:
 - small business owners

Materials

- Already Available
 - COBRA
 - Q & A — Recent Changes in Health Care Law
 - Pension & Health Coverage — Q & A for Dislocated Workers
 - Retiree Health
 - MEWAs
 - Where to Go For Information
 - How to Choose a Health Plan (for employees) - HIAA & EQP
 - Articles & Print PSAs
- To Be Developed
 - Top Ten Things to Know About your employer provided benefits.
 - Factoids
 - A series of pamphlets geared around life cycle need to know issues.
 - What You Should Know About Your Employer Provided Health Care Rights
 - A Guide for Small Businesses — Choosing a Health Plan
 - Additional PSAs
 - Expanded Website - Consumer Information on Health Care

Ongoing Initiatives

- Amicus Program
- Participant Assistance
- Enforcement Projects — ECP & MEWAs
- HIAA Implementation to include MH Parity & Mothers & Newborns
- New Claims Procedures
- SPD Reg

Proposed Campaign Launch

- Press Conference - First or second week of December.
- Partner with AFL-CIO, AFSCME, HHS, Treasury, QUIC agencies, Chamber of Commerce, EQP Group, EBRI, AARP, employers, etc. for announcement
- Announce campaign goals, target groups & message
- Promote 800 number for materials & new Website.
- Announce new Top Ten brochure & Life/Work cycle pamphlets

A LIFETIME OF HEALTH CARE PROTECTIONS FOR WOMEN
(Revised 11/9/98)

Getting the routine and acute women's health care services you need

- ▶ Proposed claims procedure rules require a timely and fair review of plan decisions to deny claims for specialist care and diagnostic tests.
- ▶ Proposed SPD regulations require plans to provide information about specialists in the plan networks and rules for accessing specialist care.
- ▶ The Department's information letter on health care quality makes clear that plan sponsors can consider a plan's patient privacy procedures when looking at plan quality.

Keeping coverage after a job change

- ▶ HIPAA protects women who need coverage of preexisting conditions and who have trouble getting insurance because of health status or genetic makeup.
- ▶ COBRA ensures coverage after losing a job or a reduction in hours.

Making the right health care decisions when you get married

- ▶ Proposed SPD regulations give women more comparative information when they are considering switching to their new spouse's plan.
- ▶ HIPAA protects women from exclusion of preexisting conditions or discrimination based on health status when they switch plans.

Getting the prenatal care you need

- ▶ HIPAA bars plans from denying coverage for prenatal care as a preexisting condition.
- ▶ Proposed claims procedure regulation helps women obtain a timely and fair review of a plan decision to deny or terminate specialist care or other needed services in the middle of difficult pregnancy, and allows prompt review of urgent care claims.
- ▶ The Newborns' and Mothers' Health Protection Act ensures adequate hospital stays for childbirth.

Caring for a child

- ▶ ERISA helps custodial parents obtain a court order to provide coverage to the children under the noncustodial parent's health plan.

- 11/16/98 MON 11:04 AM 102 119 3020 DCL/ASSY SEC/TWDA
- ▶ Proposed SPD regulation gives women information about plan rules that cover child medical support orders.
 - ▶ HIPAA protects newborn and newly adopted children with preexisting conditions.
 - ▶ The proposed claims procedure regulation provides a timely and fair review of plan denials of claims for specialist care.
 - ▶ The proposed SPD regulation provides information about access to urgent care.

Keeping coverage when a marriage ends

- ▶ COBRA provides the right to continued group plan coverage when a woman becomes separated, divorced or widowed.

Securing the right care in your later years

- ▶ HIPAA protects against discrimination based on health status and exclusion of preexisting conditions.
- ▶ Proposed claims procedure regulation provides a fair and timely appeals process for women with complex medical needs.
- ▶ Proposed SPD regulation provides information about specialists in the plan network and the plan's rules for accessing specialty care.
- ▶ The SPD regulation provides information about the plan's ability to terminate or reduce benefits.
- ▶ The Department's information letter clarifies that plans may consider data on plan quality, such as accreditation status, provider qualifications and enrollee satisfaction when selecting health plans.

Making sure your loved ones have good health care

- ▶ Proposed SPD regulation arms women with plan information on out-of-pocket costs, access to preventive and specialized care, drug coverage, and composition of the physician network so they can arrange appropriate care for ill family members.
- ▶ The proposed claims procedure regulation provides women with more information about how to file a plan appeal and why a claim was denied, so they can be more effective advocates for loved ones who are denied needed care.
- ▶ The Mental Health Parity Act helps care givers secure needed mental health care services for loved ones.

U.S. Department of Labor

Pension and Welfare Benefits Administration
Washington, D.C. 20210



DATE: 11/17

TO: Chris / Sarah / Deborah

TELEPHONE: _____ **FAX:** _____

FROM: Meredith Miller
Office of the Assistant Secretary
Pension and Welfare Benefits Administration
U. S. Department of Labor
200 Constitution Avenue, NW - Room S2524
Washington, DC 20210
(202) 219-8233 - voice
(202) 219-5526 - fax

COMMENTS:
FYI, The tentative kickoff
date is December 14.

NUMBER OF PAGES INCLUDING COVER SHEET 5

U.S. Department of Labor

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Washington, D.C. 20210

NOV 16 1998

MEMORANDUM FOR JOHN EISENBERG

Administrator
Agency for Health Care Policy and Research
Department of Health and Human ServicesFROM: MEREDITH MILLER *MM*
Deputy Assistant Secretary for Policy
Department of Labor

SUBJECT: Health Education Campaign

A number of recent developments have presented a prime opportunity to launch a Health Education Campaign within the next month. Secretary Herman would like Secretary Shalala to join her in kicking off the Campaign and in the ongoing efforts to get Americans the important health education information they need. Similar to our retirement savings education program, the health education campaign will be a public-private partnership. This timeframe is also important so that we do not lose the opportunity to serve as leaders of the health education partnership as a result of the imminent announcement of a health education campaign by the Employee Benefits Research Institute (EBRI), as discussed in more detail below. We have already had productive conversations about a number of complementary materials to include in the toolkit for the kickoff as well as additional materials to be developed for the ongoing campaign.

The Department began to lay a foundation for the Campaign sometime ago. In July of this year, we informally told stakeholders that the agency will be launching a Health Education Campaign to include possible partnerships with private sector entities. PWBA's FY2000 budget proposal includes a request for funds to support several components of the Campaign. Most recently, we met with Susan King, Assistant Secretary for Public Affairs, to outline a preliminary action plan (Attachment A). The Campaign will also come on the heels of the ERISA Advisory Council's November 13th report to the Secretary recommending an expanded health education role for the Department and coincides with the current work being done by the Quality Interagency Coordination Task Force (QUIC).

The Department's proposed role in the Campaign is described below:

Campaign message: The broad message of the Campaign could be that the Department has a unique role to play in the current flurry of health education activity taking place in the public and private sectors. First, it has a unique focus: employer-based health benefits. Second, the Department reaches out to a unique audience, i.e. key players that groups like EBRI are likely to overlook: consumers (with particular emphasis on vulnerable subgroups such as women, low wage workers, new entrants to the job market, dislocated workers and older workers), labor and

Working for America's Workforce

small businesses. Third, the Department provides health education through a unique framework — by **empowering workers with the information toolkit they need to navigate major life events that affect their health care needs**, such as changes in job or marital status or onset of a serious illness. That toolkit would include both information about legal rights (a role that DOL already plays) and “value-based purchasing”, i.e. making health care decisions based on quality as well as cost.

Campaign products: The Campaign kickoff could include the announcement of two new tools for the toolkit: a “Top Ten” brochure of what workers need to know, modeled after our pension booklet of the same title; and a guide to protections that workers have when they face major life and work events that impact on their ability to get needed health care. (A similar factsheet was prepared for the upcoming Newborns Rollout Event — Attachment B). Other tools, e.g. an expanded website, series of “life event”-specific pamphlets, and small business guides, would be developed at a later date (see Attachment A).

Impact of EBRI’s current activities on timing of DOL Campaign: After learning about the Department’s plans to launch a campaign, EBRI President Dallas Salisbury¹ approached us this summer regarding a potential partnership. Upon receiving a lukewarm response from us, he convened a kickoff meeting at the end of October. At that meeting, which was attended by PWBA staff, it was clear that he had the capability and intent to kick off his own “Consumer Health Education Campaign” (CHEC) *in November or December 1998*. EBRI appears to have the financial commitment of key ERISA industry groups as well as provider groups. (It is aiming for a three year budget \$1.5 million for three years with ten paying partners.) Although DOL and HHS were at the planning meeting, it is unlikely that EBRI’s core partners will include government, consumer groups, labor or small business. CHEC’s central message is also different that the type of message DOL is likely to convey, i.e. consumers need to be taught to change their behavior and recognize the importance of getting health care coverage.

Other DOL activities already underway that support the Campaign:

A health education campaign will serve as an efficient and effective complement to PWBA’s customer service role and to our pension education campaign. In FY 1998, PWBA received over 155,000 calls, and of those, more than half pertained to health care. Effective health education at the front end can reduce the number of disputes and wrong decisions later on, and arm workers with the self-help tools they need to resolve problems that do arise without outside assistance.

We have expanded our website to link users to useful health information, but much more needs to be done to achieve the level of effort of other public or private sector entities. To quote a recent Wall Street Journal article on how to select health care, “[t]he amount of health care information available to consumers is exploding.” Other leading newspapers and magazines have also

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recently given top billing to this issue. Our Office of Public Affairs has identified over 20,000 websites that provide this information. We plan to build more links to good consumer guides and other "tools" that have already written, as well as increase coordination with the vast health care websites of agencies such as HCFA and OPM.

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