

**STATEMENT BY
NEW YORK STATE SENATOR REVEREND RUBEN DIAZ
STATE SENATE AGING COMMITTEE
PUBLIC HEARING
250 BROADWAY, 19TH FLOOR, NYC
SEPTEMBER 8, 2009**

GOOD MORNING. I AM STATE SENATOR REVEREND RUBEN DIAZ, THE CHAIR OF THE SENATE COMMITTEE ON AGING. I WOULD LIKE TO WELCOME YOU TO THIS PUBLIC HEARING. THE PURPOSE OF THIS HEARING IS TO RECEIVE ORAL AND WRITTEN TESTIMONY REGARDING PRESIDENT BARACK OBAMA'S HEALTH CARE REFORM AND ITS IMPACT ON SENIOR CITIZENS. THIS COMMITTEE IS ESPECIALLY INTERESTED IN RECEIVING COMMENTS PERTAINING TO SECTION 1233: ADVANCED CARE PLANNING.

MUCH HAS BEEN WRITTEN AND SAID ABOUT THIS PARTICULAR SECTION OF THE BILL. IT IS MY HOPE TODAY THAT THE WITNESSES WHO ARE PRESENTING TESTIMONY WILL SEPARATE FACT FROM FICTION. I AM INTERESTED IN HEARING BOTH SIDES OF THE ISSUE, FROM THOSE WHO OPPOSE THE BILL AND THOSE WHO SUPPORT IT. I AM SURE THAT THE WITNESSES WHO ARE WITH US TODAY WILL PROVIDE THAT BALANCE.

THIS BILL, HR 3200, PROPOSES TO CHANGE SIGNIFICANTLY THE WAY HEALTH CARE IS DELIVERED IN THIS COUNTRY AND EVERY EFFORT MUST BE MADE TO ENSURE THAT THE PUBLIC HAS THE CORRECT INFORMATION. LIKewise, WE NEED TO KNOW HOW THE FEDERAL BILL WILL EFFECT NEW YORK STATE LAW. IN MY ROLE AS CHAIR OF THE SENATE COMMITTEE ON AGING, I AM PARTICULARLY INTERESTED IN HOW THE PROPOSED REFORMS WILL IMPACT SENIOR CITIZENS.

IN JULY I SENT A LETTER TO CONGRESS. MY LETTER INCLUDED MY CONCERNS THAT SECTION 1233 TARGETS SENIOR CITIZENS AND MAY PREEMPT NEW YORK STATE RULES AND PRACTICES. I STRESSED THAT THIS PROPOSED FEDERAL HEALTH CARE LEGISLATION'S IMPACT UPON THE ELDERLY CITIZENS OF NEW YORK STATE NEEDS TO BE SENSITIVE TO WHAT MAY BE CONSIDERED A "STATE'S RIGHTS" ISSUE, WHICH MAY BE BEST DEALT WITH AT THE STATE LEVEL, AND NOT IMPOSED BY WASHINGTON.

LIKE MANY, I AM CONCERNED SECTION 1233 OF HOUSE RESOLUTION 3200 MAY PUT OUR SENIOR CITIZENS ON A SLIPPERY SLOPE AND MAY DIMINISH RESPECT FOR THE INHERENT DIGNITY OF EACH OF THEIR LIVES.

AS THE CHAIR OF THE AGING COMMITTEE, I MUST STRESS THAT EACH LIFE MUST BE CHERISHED AND REGARDED WITH REVERENCE, AND THAT ANY PENDING LEGISLATION MUST PROVIDE FOR THAT GUIDELINE AND BE CAREFULLY REVIEWED.

IT WOULD BE TERRIBLE TO CONSIDER THAT ANY SENIOR CITIZEN WHO RESIDES IN NEW YORK STATE OR ANYWHERE IN THE UNITED STATES OF AMERICA SHOULD BE PLACED IN A SITUATION WHERE HE OR SHE WOULD FEEL PRESSURED TO SAVE THE GOVERNMENT MONEY BY DYING A LITTLE SOONER THAN HE OR SHE OTHERWISE WOULD. ACCORDING TO SOME EXPERTS, THE PASSAGE OF

THIS BILL COULD ENCOURAGE SENIOR CITIZENS TO SIGN END OF LIFE DIRECTIVES THAT THEY WOULD NOT OTHERWISE SIGN.

I REALIZE THAT HR 3200 IS NOT THE FINAL VERSION OF THE BILL THAT WILL BE SENT TO THE PRESIDENT FOR HIS SIGNATURE. BOTH THE HOUSE AND THE SENATE ARE SCHEDULED TO RECONVENE TODAY, AS WE SPEAK. THIS PIECE OF LEGISLATION NEEDS TO BE RECONCILED WITH THE SENATE VERSION. NEVERTHELESS, AS THE CONGRESS RESUMES ITS DEBATE ON REFORMING OUR HEALTH CARE SYSTEM, I THINK WE CAN ALL AGREE THAT TODAY'S PUBLIC HEARING IS WORTHY OF DISCUSSION AS WELL AS OUR TIME AND EFFORT.

OUR DISTINGUISHED WITNESSES TODAY ARE EXPERTS FROM MANY BACKGROUNDS: CURRENT AND FORMER ELECTED OFFICIALS, AND REPRESENTATIVES FROM NATIONAL, STATE AND LOCAL ORGANIZATIONS.

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Richard N. Gottfried
Chair
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It's About Your Life, Not "Death Panels"

Richard N. Gottfried
Chair, New York State Assembly Committee on Health
Testimony before
New York State Senate Committee on Aging
250 Broadway, New York, NY
Tuesday, September 8, 2009

My name is Richard N. Gottfried. I chair the Assembly Health Committee, and I thank the Senate Aging Committee and Chair Ruben Diaz for holding this important hearing and giving me the opportunity to testify today.

One of the most malevolent and destructive pieces of rhetoric in the national health care reform debate is the wildly dishonest claim that the proposed legislation would set up "death panels" or "rationing" that would decide whether elderly patients should live or die – "pull the plug on grandma," as they crudely put it.

The originators of this despicable lie link it to a proposal in the bill – specifically, Section 1233 of H.R. 3200 – to have Medicare offer to pay your doctor if he or she takes the time to talk with you about what your individual intentions are about end-of-life care and help you know how to write down your intentions so they can be followed.

This issue matters to all of us. In New York alone, every year, tens of thousands of patients die unable to voice their own wishes and without having provided clear instructions about their wishes. This provision of the bill would help to ensure that we know how important it is to write down our intentions so they can be followed.

The people spreading the accusation about "death panels" – whether they use that term or not – are interested in two things: (a) defeating President Obama's initiative to try to weaken him for partisan political purposes, and (b) defeating health care reform to protect various commercial interests. (Of course, some who are repeating the accusation are people who have simply believed the misinformation they have heard.) If they were truly interested in protecting life and health, they would heed what Dr. J. James Rohack, the president of the American Medical Association, says: "When people don't have health insurance, they live sicker and they die younger."¹

For years, New York State has had legislation on the books – enacted with broad bipartisan support – to promote end-of-life decision-making, and there has not been any evidence of rationing or "death panels" springing up as a result.

If more doctors would help patients to think about what they want for themselves

¹ New York Times, August 29, 2009.

and to express their intentions, that would help patients protect their right to have it their way.

In 1991, New York State enacted the Health Care Proxy law to enable people to designate a “health care agent” to make health care decisions for them if they lose the ability (“capacity”) to make their own decisions. This can include decisions about end-of-life care and providing or withholding life-sustaining treatment. Hospitals are required to give patients information about the Health Care Proxy law.

Unfortunately, just as most people have not made out a will, the vast majority of New Yorkers have not filled out and signed a health care proxy.

In 2007, we authorized the State Health Department to run education and outreach programs for patients and health care providers about the importance of patients having a health care proxy and health care providers discussing end-of-life care preferences with their patients.

In May, the Assembly unanimously passed a bill to require that when a physician or nurse practitioner is attending a patient with a terminal illness, he or she must offer to provide the patient with information and counseling about end-of-life care options, including pain management. (A. 7617, Gottfried; S. 4498, Duane.)

In July, the State Senate unanimously passed the Family Health Care Decisions Act to enable family members, instead of strangers, to make health care decisions for a patient who does not have decision-making capacity or a written health care proxy. (It still has to pass the Assembly.) (A. 7729-C, Gottfried; S. 3164-A, Duane.)

The Family Health Care Decisions bill is not about the “right to die.” Strengthening end-of-life decision-making protects the rights of patients and their families on the patient’s behalf. The New York Civil Liberties Union and the New York State Right to Life Committee endorse the Family Health Care Decisions Act. The Right to Life Committee’s statement says the bill “protect(s) the rights of people, especially those with disabilities, who choose life-sustaining medical treatment or food and fluids, to have their choices respected,” even where the patient’s health care provider disagrees.

What New York State has not done is to offer to compensate health care providers who take the time for this important counseling. It’s terrific that Congress is considering having Medicare make that offer.

It is shameful that this decent, thoughtful, and pro-patient provision is being deliberately misrepresented to try to defeat health care reform. It would also be a shame if Congress lets this provision get shouted down.

People who care about health care, including the health care of grandparents like me and you, Mr. Chairman, should support health care reform and especially should support Section 1233 of H.R. 3200.

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**Public Hearing Held by the
New York State Senate Aging Committee**

Sponsored by Senator Ruben Diaz:

Impact of H.R. 3200 on Seniors

September 8, 2009

**Testimony of Betsy McCaughey, Ph.D.
Chairman/Founder of the Committee to Reduce Infection Deaths
And Former Lt. Governor of New York State**

I want to thank Senator Diaz for inviting me to this forum, and for taking the initiative to discuss this critical issue. I am a patient advocate and former Lt. Governor of New York State. In 2004, I founded the Committee to Reduce Infection Deaths (or RID), a nationwide educational campaign to stop hospital-acquired infections. In five years, RID has made hospital infections a major public issue, providing compelling evidence that preventing infection improves hospital profitability as well as saving lives. RID has won legislation in over 25 states for public reporting of infection rates. RID has become synonymous with patient safety and clean hospital care.

I have authored over one hundred scholarly and popular articles on health policy, infection, medical innovation, the economics of aging, and Medicare, which have appeared in many national publications. My 1994 analysis of the dangers of the Clinton health plan in the *New Republic* won a National Magazine Award for the best article in the nation on public policy.

From 1995 to 1998, I served as Lt. Governor of New York State. I focused on health issues, and I was at the forefront in the fight against HMO abuses like drive-thru deliveries and drive-thru mastectomies. My bills banning these abuses and others like these became models for legislation in many states and in Congress. Now I am fighting to protect access to and quality of care for seniors, which is endangered by the current health bills in Congress.

Since Medicare was established in 1965, access to care has enabled older Americans to avoid becoming disabled and languishing in nursing homes. But legislation now being rushed through Congress -- H.R. 3200 -- will reduce access to care, pressure the elderly to end their lives prematurely, and doom baby boomers to painful later years.

The Congressional majority wants to pay for its \$1 trillion to \$1.6 trillion health bills with new taxes and a \$500 billion or greater cut to Medicare. This cut will come just as baby boomers turn 65 and increase Medicare enrollment by 30%. Less money and more patients will necessitate rationing. The Congressional Budget Office estimates that only 1% of Medicare cuts will come from eliminating fraud, waste and abuse.

The assault against seniors began with the stimulus package in February. Slipped into the bill was substantial funding for comparative effectiveness research, which is generally code for limiting care based on the patient's age. Economists are familiar with the formula, where the cost of a treatment is divided by the number of years (called QALYs, or quality-adjusted life years) that the patient is likely to benefit. In Britain, the formula leads to denying treatments for older patients who have fewer years to benefit from care than younger patients.

When comparative effectiveness research appeared in the stimulus bill, Rep. Charles Boustany Jr., (R., La.) a heart surgeon, warned that it would lead to "denying seniors and the disabled lifesaving care." He and Sen. Jon Kyl (R., Ariz.) proposed amendments to no avail that would have barred the federal government from using the research to eliminate treatments for the elderly or deny care based on age.

In a letter this week to House Speaker Nancy Pelosi, White House budget chief Peter Orszag urged Congress to delegate its authority over Medicare to a newly created body within the executive branch. This measure is designed to circumvent the democratic process and avoid accountability to the public for cuts in benefits.

Driving these cuts is the misconception that preventative care can eliminate sickness. As President Obama said in a speech to the American Medical Association: "We have to avoid illness and disease in the first place." That would make sense if most diseases were preventable. But the two most prevalent diseases of aging -- cancer and heart disease -- are largely caused by genetics and their occurrence increases with age. Your risk of being diagnosed with cancer doubles from age 50 to 60, according to the National Cancer Institute.

The House bill shifts resources from specialty medicine to primary care based on the misconception that Americans overuse specialist care and drive up costs in the process (pp. 660-686). In fact, heart-disease patients treated by generalists instead of specialists are often misdiagnosed and treated incorrectly. They are readmitted to the hospital more frequently, and die sooner.

"Study after study shows that cardiologists adhere to guidelines better than primary care doctors," according to Jeffrey Moses, a heart specialist at New York Presbyterian Hospital. Adds Jeffrey Borer, chairman of medicine at SUNY Downstate Medical Center: "Seldom do generalists have the knowledge to identify the symptoms of aortic valve disease, even though more than 10% of people over 75 have it. After valve surgery, patients who were too short of breath to walk can resume a normal life into their 80s or 90s."

While the House bill being pushed by the president reduces access to such cures and specialists, it ensures that seniors are counseled on end-of-life options, including refusing nutrition where state law allows it (pp. 425-446). In Oregon, the state is denying some cancer patients care that could extend their lives and is offering them physician-assisted suicide instead.

The harshest misconception underlying the legislation is that living longer burdens society. Medicare data prove this is untrue. A patient who dies at 67 spends three times as much on health care at the end of life as a patient who lives to 90, according to Dr. Herbert Pardes, CEO of New York Presbyterian Medical Center.

What is costly is when seniors become disabled. In a 2007 Health Affairs article, researchers reported that surgeries to unclog arteries and replace worn out hips and knees have had a major impact on steadily reducing disability rates. And nondisabled seniors use only one-seventh as much health care as disabled seniors. As a result, the annual increase in per capita health spending on the elderly is less than for the rest of the population.

Nevertheless, Medicare is running out of money. The problem is the number of seniors compared with the smaller number of workers supporting the system with payroll taxes. To remedy the problem, the Congressional Budget Office has suggested inching up the eligibility age one month per year until it reaches age 70 in 2043, or asking wealthy seniors to pay more.

These are reasonable solutions -- reducing access to treatments and counseling seniors about cutting life short are not. Medicare has made living to a ripe old age a good value. ObamaCare will undo that.

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**PUBLIC HEARING ON HR. 3200: AMERICA'S AFFORDABLE HEALTH
CHOICES ACT OF 2009 AND ITS IMPACT ON SENIOR CITIZENS
SENATOR RUBEN DIAZ, SR
CHAIR, COMMITTEE ON AGING
SEPTEMBER 8, 2009**

CSCS is the central organization in NYC with over 200 member agencies providing a broad array of community-based services for 300,000 older New Yorkers including: multi-service senior centers, nutrition, case management, home care, health and wellness programs, adult day services, NORCs, transportation, elder abuse services, intergenerational programs, housing, mental health services, bill paying, ESL and services for immigrants, cultural and educational events, voluntarism and other services.

It is widely recognized by Americans across the country that our health care system is broken. Millions have no health care coverage with 14,000 people a day losing their coverage. Millions more have inadequate coverage and find themselves fighting with their insurer at a time they should be concerned about getting proper treatment and healing. Thousands of Americans file for bankruptcy due to inability to pay their medical bills. As a candidate, President Barack Obama made health care reform a priority so it is no surprise that he has made it a top priority in his administration. Americans voted him in as President and gave Democrats a majority in both houses of Congress – they want meaningful action on health care reform.

Some say it isn't the right time. However, we've heard it isn't the right time since 1935 when President Franklin D. Roosevelt tried to include universal health care as part of Social Security. It wasn't the right time until 1965 when President Lyndon Johnson got Medicare and Medicaid passed. It wasn't the right time in the early 1990's when President Bill Clinton and Hillary Clinton tried to get health care reform through Congress. Here we are in 2009 and we are still hearing it's not the right time for health care reform. If you have ever had a problem with the American health care system or know people who have, you know that not only is it the right time now – but we are way overdue for dramatic changes. Shameful and life threatening stories abound as we all know well.

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Medicare, as one of the most successful public programs ever initiated in this country, is largely responsible for increasing both the quality of life and longevity of Americans. It is a very popular government-run single-payer program. The "debate" on health care reform is really about reforming health insurance. A single payer system, a "Medicare for all" has not even found a place at the legislative table in Congress or the White House. Already, this is a substantial compromise on the part of many Congressmembers and Americans. Instead of a thoughtful, meaningful debate on health care reform, we are subjected to radical, false claims about what HR3200 would do to senior citizens. Phrases like "death panels" and "pull the plug on grandma" have become part of our daily lexicon when talking about health care reform. The latest targets of scare tactics have been veterans and women with breast cancer – claims being made these groups would not get proper care. These claims are intended to scare people into opposing health care reform and, unfortunately, they have an

impact. But leadership is about not accepting these scare tactics and standing up against those who foster them, not pandering to them as too many elected officials are doing at town hall meetings and other forums across the country. After reading Section 1233, "Advance Care Planning Consultation", in HR3200, it is evident that the idea of "death panels" is totally ungrounded:

- Section (5) "actionable medical order relating to the treatment of that individual that"...section (5)(A)(ii), "effectively communicates the **individual's preferences regarding life sustaining treatment** (emphasis added), including an indication of the treatment and care desired by the individual;"
- Section (5)(B) states, "The level of treatment indicated under (A)(ii) **may range from an indication for full treatment to an indication to limit some or all specified interventions.** (emphasis added) This section goes on to delineate a variety of interventions a person may choose "among other items"
- Section (5) goes on to state, "...the Secretary shall **include quality measures on end of life care and advanced care planning that have been adopted or endorsed by a consensus-based organization, if appropriate.**" (emphasis added) So, no one person is making any determinations of appropriate end of life care.

I have a living will and health care proxy. So does my 91 year old mother and other members of my family and friends. It is progress to have Medicare cover the cost of individuals developing their end of life plan with a health care professional and was originally inserted as part of the Medicare Part D legislation passed in 2006 under President George Bush. No one objected to this then and some now objecting voted for this as part of the Medicare Part D legislation without a problem. So, why are the voices so loud opposed to this now? Rather than a "death panel", this should be called "end of life dignity". For politics not to

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rise above the seriousness of the issue of advance care planning is shameful and damaging to the lives of millions of Americans and their family caregivers at the most sensitive time of their lives.

We all want to be in control of our decisions for as long as possible. We also know that at some point we may have to leave those decisions to those we trust. In the middle of a serious or terminal illness is not the time to put the family through this difficult process. Again, the voice of the individual whose life this is should be heard above all in advance of a crisis situation.

According to the Medicare Rights Center, HR3200 strengthens Medicare:

- Adds five years of funding to Medicare's Hospital Insurance Trust Fund, which is now projected to run short of money by 2017. It strengthens Medicare's finances primarily by reducing annual increases to hospitals, nursing homes and home health agencies. It also brings subsidies to Medicare private plans in line with costs under the original Medicare.
- The government will not come between you and your doctor to make health care decisions and nothing in HR3200 rations care or prevents Medicare from treatment for a terminal illness.
- HR3200 eliminates copays and deductibles for preventive services. It allows low income people to receive financial assistance for their medical and drug costs and to still keep some personal savings.
- The bill will reduce the number of individuals who return to the hospital because they were not provided with an appropriate discharge care plan.

The bill makes hospitals financially responsible for ensuring Medicare recipients receive proper care after discharge.

- HR3200 increases Medicare payments for consultations with primary care physicians and specialists as well as providing bonuses to primary care doctors. The bill funds over \$200 billion in Medicare payments to doctors as well as other benefits.

Additional Medicare benefits in health care reform package:

- Eliminates the Part D “donut hole” over 15 years starting with a \$500 reduction in 2011. The additional cost will be paid for by negotiating prices (rebates) with pharmaceutical manufacturers. This is an issue Senator Diaz has worked on on a state level.
- Permits Part D enrollees to make a mid-year change if their coverage is reduced or cost sharing is increased for a drug.
- Establishes new penalties for false or misleading marketing by Part D plans.
- Increases the asset limit for low income older adults for Medicare Part D and Medicare Savings programs to \$17,000 for individuals and \$34,000 for couples, effective January 1, 2012 and indexes the asset limit to inflation. This is a significant increase in the asset level. Also extends the Qualified Individuals (Q1) program that provides Part B premium assistance to low income Medicare beneficiaries.

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- Allows individuals to self-certify income and assets (with administrative verification) when applying for the Low Income Subsidy (LIS) under Part D as of 2010. The complexity of the application process has been a major barrier to enrollment for low income seniors.
- Requires drug companies to provide rebates for dual eligibles enrolled in Part D plans.
- Eliminates a 21% cut in physician fees planned for 2011, and provides increased reimbursements for primary care, as stated previously. Overall, 72% of increased Medicare spending over the next ten years is for physician payments.

Need to discuss community-based longterm care –

CSCS’ recently released policy paper, “No Time to Wait: The Case for Long Term Care Reform: Recommendations for Modernizing Long Term Care in New York”, includes 31 major policy and programmatic recommendations to build a sustainable, consumer-friendly, community-based long term care system in NY. It is these issues that need substantive discussion and action to ensure that older New Yorkers can age in place in their homes and communities with dignity and the services they require. The full report is on the CSCS website –

www.cscs-ny.org

The CLASS Act (H.R.1721/S.697) – Longterm care insurance coverage -

According to the Elder Economic Security Standard Index, an initiative through Wider Opportunities for Women, the cost of home and community-based services range from **\$7,322 per year to \$41,871** per year depending on the level of care required. Seniors who cannot afford the home and community-based services they need must spend down their retirement savings to become eligible for public assistance, most often state and federal Medicaid dollars, to pay for the care they need. Enactment of the CLASS Act as part of health care reform is a top priority for national and local aging organizations.

Budget Neutral - In today’s economic climate, spending concerns are a top

priority. The CLASS Act offers a fiscally responsible approach that is both budget neutral and limits Medicaid spending.

Balanced - The CLASS Act works within the current health care system by sustaining the role of private health and long-term care insurance while creating a public long-term care insurance program. Lack of affordability to purchase longterm care insurance is a major barrier right now. As such, the CLASS Act is not designed to cover the full cost of long term care services. The bill acknowledges the role for private insurance and/or personal savings in covering the remainder of costs. Estimates show that services provided under the CLASS Act will cover one quarter to one half of the cost for home and community-based services. In sum, the bill balances the responsibility of the public and private sectors to ensure the health and economic well-being of our nation's seniors.

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The status quo is not an option. We cannot let ourselves as government and community leaders, and as a nation, get distracted by purposefully misleading, scare tactics that will result in decades more of a health care system that is sorely broken, shameful and not cost-effective. The health care system will grow increasingly unsustainable in cost and its inability to provide health care for all Americans.

Older Americans also care about health coverage for their families. Those adults, who haven't quite reached Medicare age 65 yet, also often need affordable health care coverage. Both House and Senate proposals would reform the private health insurance market through changes such as:

- Prohibiting pre-existing conditions
- Requiring an annual out-of-pocket spending limit for individuals and families
- Preventing different premiums being charged based on gender, health status or occupation
- No annual lifetime limits on coverage

Websites providing independent, objective information about health care reform:

- www.kff.org - the Kaiser Family Foundation
- www.politifact.com – a project of the St. Petersburg Times to check the accuracy of certain political statements
- www.factcheck.org – a project of the Annenberg Public Policy Center

Wendell Potter, the former head of public relations with Cigna, one of the largest health insurance companies, is now a chief whistleblower speaking out on the abuses of health insurance providers. His interview with Bill Moyers is very revealing as to how the health insurance industry has worked to use less and less money to pay claims and keep the status quo in current efforts to reform health care: <http://www.youtube.com/watch?v=Mv1FwOCNoZ8>

Thank you for the opportunity to testify on this most pressing national problem – the need to enact meaningful health care reform.



September 2, 2009

The Honorable George Miller, Chair
Committee on Education & Labor
2181 Rayburn House Office Building
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Charles B. Rangel, Chair
Committee on Ways and Means
1102 Longworth House Office Building
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Henry A. Waxman, Chair
Committee on Energy and Commerce
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairmen Miller, Rangel and Waxman:

Thank you for your attention to the needs of older adults in H.R. 3200, America's Affordable Health Choices Act. This legislation makes major advances in our health system's capacity to provide high-quality care for all Americans. The undersigned members of the Leadership Council of Aging Organizations (LCAO) support those provisions of the bill that help seniors, but we urge you to consider some additional changes to ensure that quality health care is affordable for older Americans. The LCAO is a coalition of 60 national not-for-profit organizations concerned with the well-being of America's older adults, the fastest growing population segment of our country.

We strongly support and urge you to maintain provisions for:

- ☑ Elimination of the coverage gap in Medicare Part D;
- ☑ Mandatory Medicare Part D price rebates;
- ☑ Discounts of 50% for brand-name drugs for enrollees in the "doughnut hole," in the interim as the gap is closed;
- ☑ Requiring the Secretary of HHS to negotiate drug prices under Medicare Part D (Schakowsky amendment, Energy & Commerce Mark-Up);
- ☑ Establishment of a new asset test (\$17,000 for individuals and \$34,000 for couples indexed annually by CPI) for low-income individuals for eligibility determinations for the Part D Low-Income Subsidy (LIS) and the Medicare Savings Programs;
- ☑ Authorization of information sharing between the IRS and Social Security Administration to assist SSA in outreach to individuals who are eligible for the Part D LIS;
- ☑ Use of an enrollment process for subsidy-eligible individuals into Part D plans that takes into account the quality, cost and/or formulary of the plan;
- ☑ A temporary reinsurance program for retirees;
- ☑ Limitation of beneficiary cost-sharing amounts under Medicare Advantage plans to cost sharing amounts under traditional Medicare;
- ☑ Reducing excess payments to Medicare Advantage private plans;
- ☑ Nursing home transparency requirements;

- ☐ Criminal background checks for direct care staff in long-term care facilities (Schakowsky amendment, Energy & Commerce Mark-Up);
- ☐ CLASS Act provisions (Pallone amendment, Energy & Commerce Mark-Up); and
- ☐ Independence at Home Medical Practice Pilot Program (Markey amendment, Energy & Commerce Mark-Up).

We encourage you to continue to consider the needs of older Americans as you amend and work

to reconcile the reports of H.R. 3200 by the three committees, including in the following areas:

Medicare: Policy proposals that emerge from any new Medicare commission or council should be evaluated and approved by Congress under the rules that apply for most legislation. In addition, global spending targets and mandatory benefit cuts should not be employed to achieve program savings. Rather, efficiency and quality should be enhanced through careful delivery system reforms. Any payment innovations and cost containment efforts should be shared among all health purchasers, including Medicare and private health insurance plans participating in the Exchange. Policies to adjust provider payments should ensure that beneficiaries maintain access to quality health care and that providers' essential operations – such as recruiting, training, and retaining qualified staff – can be sustained. It is crucial that access to high quality care be maintained across outpatient, hospital, post-acute, and community settings.

Affordability: For many Americans over the age of 50, but not yet eligible for Medicare, the cost of health insurance is prohibitively high. We urge you to balance the different parts of the affordability equation in ways that address this barrier to appropriate and affordable health care. In particular, we ask that you pay special attention to the needs of those moderate-income people over 50 who may not qualify for Medicaid or subsidies, yet still cannot afford to pay substantial percentages of their incomes for premiums and out-of-pocket expenses. We urge you to eliminate provisions allowing age rating, to provide a stop loss benefit for all Americans, and to broaden eligibility for subsidies in order to ensure that health care reform truly provides comprehensive and affordable coverage for older Americans.

Low-Income Individuals: We applaud provisions in H.R. 3200 to raise the Medicaid income eligibility level to 133 percent of poverty for individuals under age 65. However, we urge you to include people over the age of 65 in this expansion in order to avoid the unintended consequence of low-income individuals experiencing greatly-increased health care costs when they become eligible for Medicare. Alternatively, these individuals could be assisted by raising the income eligibility level for the Qualified Medicare Beneficiary program to 133 percent of the federal poverty line.

Prevention and Wellness:

LCAO appreciates the breadth and depth of the prevention and wellness elements of the House draft bill. However, we have concerns about all of the nation's prevention and wellness funding being solely distributed through the Centers for Disease Control and Prevention (CDC). We urge you not to exclude or override existing programs already proven to be effective, such as evidence-based health promotion and disease prevention programs led by the U.S.

Administration on Aging (AoA) since 2003 and delivered locally through the Aging Services Network. In addition to CDC and AoA, there are additional Department of Health and Human Services (HHS) agencies doing effective work in the prevention and wellness arena (e.g., the Substance Abuse and Mental Health Services Administration, the Centers for Medicare and Medicaid Services, and the Agency for Healthcare Research and Quality). We urge you to ensure that the language on prevention and wellness programs gives authority to the Secretary of HHS to best determine which agencies should administer particular programs; respects

existing, proven programs already at work in communities; encourages a role for groups representing the interests of targeted populations; and makes clear the role of AoA and the Aging Services Network in programming directed toward the age 60 and older population.

Improve Long-Term Supports and Services Provisions:

LCAO believes that any major health reform legislation must include strong provisions on long-term services and supports (LTSS). We simply cannot wait to address this area of health care, which is a major driver of costs and is of critical importance to Americans of all ages. Our current system forces people into institutions inappropriately, requires many to spend-down into poverty before receiving the help they need, fails to provide realistic opportunities for personal planning, and fails to support family caregivers adequately. For many Americans, private insurance plans for disability and long-term care are simply an unavailable or unaffordable option. True reform must include substantial reforms of how long-term services and supports are delivered – strengthening Medicaid home and community-based services, improving the financing and administration of effective programs, and establishing a new, voluntary national long-term care insurance program. LCAO supports several bills that should be included in your health reform legislation, including the CLASS Act (H.R. 1721, some provisions of which were included in the successful Pallone amendment to H.R. 3200), Empowered at Home (H.R. 2688), and *Project 2020: Building on the Promise of Home and Community-Based Services* (H.R. 2852).

Thank you again for your work to bring affordable, quality health care to every American. Please do not hesitate to call on us for any additional information you may require as you continue movement toward a final package.

Sincerely,

AARP

AFSCME Retirees

Alliance for Retired Americans

American Association of Homes and Services for the Aging

American Federation of Teachers Program on Retirement and Retirees

American Society on Aging

Association for Gerontology and Human Development in Historically Black Colleges and Universities

Association of Jewish Aging Services of North America

B'Nai B'Rith International

Center for Medicare Advocacy

Easter Seals

The Gerontological Society of America

Gray Panthers

Lutheran Services in America

National Academy of Elder Law Attorneys

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association for Hispanic Elderly

National Association of Area Agencies on Aging

National Association of Foster Grandparent Program Directors

National Association of Professional Geriatric Care Managers

National Association of State Long-Term Care Ombudsman Programs

National Caucus and Center on Black Aged, Inc.

National Committee to Preserve Social Security and Medicare

National Council on Aging
National Hispanic Council on Aging
National Indian Council on Aging
National Senior Citizens Law Center
NCCNHR: The National Consumer Voice for Quality Long-Term Care
OWL - The Voice of Midlife and Older Women
Service Employees International Union
Volunteers of America
Wider Opportunities for Women (WOW)

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Testimony of Paul Malley, President of Aging with Dignity New York State Senate Committee on Aging Public Hearing "America's Affordable Health Choices Act of 2009 and Its Impact on Senior Citizens" *New York City – September 8, 2009*

Chairman Diaz and members of the New York Senate Committee on Aging, I am pleased to have the opportunity to contribute to this important conversation and I thank you for focusing attention on the impact of proposed health care reform measures on senior citizens. My name is Paul Malley and I am President of the national nonprofit organization Aging with Dignity, based in Tallahassee, Florida. Aging with Dignity has championed the cause of advance care planning for more than 12 years, during which time we have helped more than 13 million Americans discuss and plan for the kind of care they would want at the end of life. I thank you for focusing this hearing especially on Section 1233 of the current U.S. House Resolution 3200. As advocates for quality end-of-life care and advance care planning, we wholeheartedly support the concept of patients consulting with their doctors in these matters. While we support this concept overall, we have serious concerns about the practical implications of the current Section 1233 on seniors and other vulnerable populations.

Aging with Dignity Background

Aging with Dignity was founded in 1996 with generous support from the Robert Wood Johnson Foundation and others concerned with improving end-of-life care and protecting the dignity of all Americans as they age. We remain a private, nonprofit, and nonpartisan organization that has never taken federal or state grant dollars. Our organization was founded by Jim Towey, who was legal counsel to Mother Teresa of Calcutta for 12 years until her death. He also worked in her missions in Calcutta and Tijuana, and for a year, as a full time live-in volunteer at her home for AIDS patients in Washington, D.C. It was this experience of caring for those near the end of life that inspired Jim to found Aging with Dignity. Aging with Dignity is the creator and distributor of the advance directive Five Wishes, which is the closest thing there is in America to a national advance directive/living will. Five Wishes currently meets the legal requirements of 40 states, including New York, and it is useful

in all 50 states in beginning and structuring end-of-life discussions that result in a completed advance directive. It is unlike all other advance directives in that it is easy to understand and use and includes the personal, family and spiritual issues that people say matter most to them.

Since its national introduction in 1998, some 15,000 partner organizations have distributed more than 13 million copies of Five Wishes in all 50 states and overseas. These organizations include places of worship, physicians, hospitals, hospices, health systems, attorneys, financial planners and others. Here in New York more than 400 organizations have distributed Five Wishes around the state – the City of Yonkers provided it to employees, and a few years ago even MTV provided Five Wishes for its young workforce.

In 2006 we received a grant from the United Health Foundation to make Five Wishes available to groups whose first language is not English. Today, Five Wishes is available in 23 languages and in Braille. This is especially important in a diverse country where 47 million people (18%) speak a language other than English at home – and even more so in the State of New York where about 30% of people speak languages other than English at home – and 13% speak English “less than very well.”¹ We believe Five Wishes has literally changed the way people talk about and plan for end-of-life care. In my 11 years at Aging with Dignity – seven years as the organization’s president – I have given countless advance care planning workshops at senior centers, workplaces, hospitals, places of worship, colleges, and other venues. It is clear that when people talk about caring for someone at the end of life, they want to talk about what matters most to them: their family relationships, comfort, human dignity, and spirituality. For too long the advance care planning conversation focused only on the issues that matter to doctors and lawyers – life support treatment and powers of attorney. It is no wonder that most people have not completed an advance directive. That is the change that Five Wishes brought to the table. It took what was an abstract legal and medical process and reframed the discussion and document in terms that make sense to people, regarding the issues that matter most. When the document is easier to understand, it becomes easier to have the all-important conversation about end-of-life preferences with loved ones and doctors.

Impact of H.R. 3200 – Section 1233

The proposed House health care legislation encourages these conversations between doctor and patient, and while we believe that this is important and good, that conversation should come after one already held in the living room between the patient, spouse and family. People tend to avoid this conversation if the discussion is centered around feeding tubes, comas, ventilators and terminal illness. In contrast, they are much more comfortable talking about it when the conversation deals with how they wish to be cared for, or how they would want their pain managed, or what things are important in their life that they want people to know. Legal and medical decisions are important, but these are the topics that speak to the person’s God-given

dignity and value as a person. It is important that we care for people, not because it is cost-effective, but because relieving pain and curing illness are worthy goals of a compassionate society.

1 Shin HB, Bruno R. Language Use and English-Speaking Ability: 2000. U.S. Department of Commerce Census Bureau, October 2003.

We believe that advance care planning must always put the patient first and allow people to state in their own words what kind of treatment they want or don't want in case of serious illness or impending death. While the doctor is a valuable resource, the decision on what to do or not do should be the patients. When that decision is made it should be respected and the patient must be able to change his wishes at any time.

Advance Care Planning Communication

At the heart of good advance care planning is good communication, first within the family, and then between doctor and patient. It is never enough to just sign the advance directive and be done with it. We have always encouraged the follow-up conversation with the physician so that a person's wishes are fully understood. A communications study revealed that when doctors talk to patients about advance directives, the average conversation lasts 5.6 minutes and the doctor talks for two-thirds of this time.

2 Additionally, when doctors do talk to patients about advance directives, the discussion infrequently addresses patients' values and attitudes toward uncertainty, making the discussions less useful in decision making.

3 It is also acknowledged that traditional advance directive documents may not effectively stimulate this form of physician-patient communication.

4 Any new policies adopted should make it easier for these conversations to occur and provide the doctor with enough time to engage in true consultation. Section 1233 takes a step in the right direction by promoting patient-doctor communication. But the key is to make it a patient-centered process that gives the person the most control possible over his or her individual care. This is what Congress intended when it passed the original Patient Self-Determination Act in 1990.

Medical Orders vs. Advance Directives

The current House proposal threatens to undo all that progress and re-medicalize the discussion, essentially making patients spectators in their own health care decisions again. For example, the proposal says the physician-patient conversation shall include an explanation of the benefits of medical

“orders for life sustaining treatments.” This would enshrine and define the concept of orders for life sustaining treatment for the first time in federal law. The medical orders model has the potential to shift end-of-life decision making away from the patient. This is the mechanism many fear will lead to the patient feeling pressured into consenting to the doctor’s orders.

2 *Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the Black Box: How do Physicians Communicate about Advance Directives? Ann Intern Med. 1998;129:441-449.*

3 *Larson DG, Tobin DR. End-of-Life Conversations: Evolving Practice and Theory. JAMA. 2000;284(12): 1573-1578.*

4 *Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelsohn DC. Reconceptualizing Advance Care Planning from the Patient’s Perspective. Arch Intern Med. Vol 158. Apr 27, 1998: 879-884.*

The shift is important to understand. As it exists now, an advance directive expresses a patient’s wishes regarding life support treatment if they become seriously ill and life support treatment would only delay the moment of death. The person can change his mind at any time. However, the orders for life sustaining treatment model results in a signed medical order that could state that no life support treatment, or antibiotics, or tube feeding, be offered the patient even if these treatments could help, and regardless of what family members may request. Once the order has been signed by a physician, it remains in effect until changed. This medical order model may be appropriate for someone close to death, but it is not at all appropriate for an otherwise healthy Medicare recipient. The distinction should be made clear in the legislation.

Supporters of the medical order model say it was developed in Oregon to overcome the limitations of do-not-resuscitate orders. It aims to convert treatment preference in to medical orders that can be followed by medical personnel regardless of where the patient is located.

5 Unlike an advance directive that is triggered only in specific situations, the medical order does not depend on your health getting worse. It does not think ahead to future situations, it is only about the here and now. There is a huge difference between patients making decisions in their own words and on their own turf, and a process where the decisions are written in a medical order created by and for health care providers. Because New York is one of the few states where these medical orders are already established, the doctors and residents of this state would be impacted by the requirement that doctors shall explain “the reasons why the development of such an order is beneficial to the individual...” I want to be very clear in my comments regarding medical

orders. There are times when these orders can be very useful. Indeed, much work has been done on this issue in the State of New York regarding Medical Orders for Life Sustaining Treatment (MOLST). My objection is found in the requirement established in Section 1233 that doctors must tell Medicare patients about the benefits of these orders if they want to be reimbursed for the consultation, without regard to the condition of the patient and whether or not such an order is appropriate.

5 Hickman SE, Nelson CA, Moss AH, Hammes BJ, Terwilliger A, Jackson A, Tolle SW. Use of the Physician Orders for Life Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting. Journal of Palliative Medicine 2009; 12(2). 133-141.

Physician as Salesman

We urge Congress to abandon any approach that waters down patient rights. It must also stop any attempts to inject the government into doctor-patient conversations. The current House proposal does indeed make the doctor-patient end-of-life discussion voluntary, not mandatory, but it overreaches inappropriately when it specifies what the doctor and patient must discuss in order for the doctor to be paid. It goes too far when it instructs the physicians to “include an explanation of the *benefits* of medical orders for life sustaining treatments.” The government should not put the doctor in the position of having to “sell” the patient on the benefits of medical orders for life sustaining treatment.

Federal Usurpation

We believe that state legislatures should also be very concerned over federal usurpation of state powers, which are part of this legislation. The U.S. House legislation carefully defines how states are to adopt the medical orders for life sustaining treatment; how such policies should be formed; what organizations must be part of the committee; and how and where the orders will be honored. These are properly the realm of state lawmakers and their departments of health, not members of Congress or the Secretary of Health & Human Services. We can easily see how a federal regulator, under the rubric of “quality improvement,” could, over time, ratchet up the control it exerts over its affiliated providers.

It is curious that with so much attention given to mandating the details of the medical order model, one very important question remains unanswered. For whom is the medical order appropriate? The current provision requires doctors wanting reimbursement to tell Medicare patients about the benefits of these medical orders. However, these orders are intended for people who already have an advanced chronic illness, for whom the prognosis is measured in 1 to 2 years.

6 That certainly does not include every Medicare recipient. Should the Congress decide to use this opportunity to define the medical order model for the first time in federal law, it should include in its mandate for the states the distinction that these medical orders are only intended for people near the end of life.

6 Meier DE, Beresford L. POLST Offers Next Stage in Honoring Patient Preferences. Journal of Palliative Medicine. April 2009, 12(4): 291-295. Page 6 of 8

Assisted Suicide?

Still another concern is that the legislation also instructs the physician to include “the continuum of end-of-life services and supports available,” including providing a list of state and national informational “clearinghouses.” Doctors should absolutely talk about the benefits of hospice and palliative care as part of the continuum. Physicians should refer patients to hospice as soon as appropriate – often the referral happens too late for the patient to receive the full benefit of this high-quality care. The full “continuum” provision sounds innocent enough, but such a list or clearinghouse would likely include options recommended by groups like the Hemlock Society, now euphemistically calling itself “Compassion & Choices.” Advocates of physician-assisted suicide successfully argued for this type of requirement in California, knowing that if assisted suicide is legalized doctors will be forced to tell patients about the option as part of the “continuum.” The House legislation would impart a similar requirement on physicians when they have a Medicare-reimbursable consultation on advance care planning. This has already suddenly become a very real issue in the states of Washington, Oregon and Montana. When the government has a vested interest in holding down costs, is it beyond the realm of possibility to imagine it encouraging citizens to forego care? Recall the woman in Oregon who last year was told by state-administered Oregon Health Plan that it would not pay for her cancer treatment, but would pay for her suicide drugs. I cite this reference because this fear is what drives all the talk and concern about “death panels” and “death books.” It is a very real fear that this legislation needlessly stokes. Indeed, the Hemlock Society has publically stated that passage of this portion of the legislation is its highest legislative priority.

Vulnerable groups

Studies estimate that about one-quarter of the U.S. adult population is functionally illiterate. Even higher numbers of people have difficulty understanding most health documents. This is not confined to small pockets of the population. Specifically, research shows that many independent, community-dwelling elderly people do not have the literacy skills necessary to function adequately in the health care environment.

7 Vulnerable populations – the disabled, those with expensive-to-treat conditions, the uninsured, people with cognitive impairments, people with no or few family members and those with low health literacy – also have good reason for concern. They rightly fear the logical conclusion of any discussion that frames life in terms of its quality or its value to others. This is what the recent concern over the VA's use of "Your Life, Your Choices" is all about. If what it advocates becomes the norm, it will have an immediate impact on New York's 1.1 million veterans (many of whom receive care in New York's 12 VA medical centers), and ultimately on every New Yorker and every American. I am familiar with "Your Life, Your Choices" because our founder Jim Towey and I were the first to raise concerns about it in 2007. Due to the flawed content, it was removed from circulation in November 2007 and remained that way until recently. Last month "Your Life, Your Choices" appeared again on the VA website along with a new edition of the VA handbook on advance care planning that instructs physicians to refer patients to "Your Life, Your Choices."

7 Parker, R. Health Literacy: a Challenge for American Patients and their Health Care Providers. Health Promotion International, Oxford University Press. 2000 Vol 15 No 4: 277-283. 8 Fagerlin A, Schneider CE. Enough: The Failure of the Living Will. The Hastings Center Report, Vol 34, 2004.

U.S. Veterans Administration – "Your Life, Your Choices"

"Your Life, Your Choices" is a massive taxpayer-funded guide that turns good advance care planning upside down and gives it a bad name. Its focus is on situations when, faced with a disability or serious illness, people may consider life not worth living. For example, it asks veterans to consider if life is worth living if they can't walk, can't meaningfully contribute to their family, are a financial burden, live in a nursing home, or can't "shake the blues." After this exercise, veterans are asked to write down their decisions about medical care and decide at what point they would rather forego medical treatments. In other words, it frames the discussion in such a way that it asks them at what point their life just isn't worth living anymore.

The context in which veterans are guided to make end-of-life decisions is significant because the way questions are asked and framed impacts the answer. When given the same case scenario with different descriptions of the intervention, seventy-seven percent of elderly people in one study changed their minds at least once. When the language was phrased negatively, they were more inclined to forego medical intervention.

8 This standard for medical decision making – a “life not worth living” approach to advance care planning – should have no place in any health care system, and certainly not one set up to serve those who have served in the nation’s armed forces. Indeed, the fingerprints of the assisted suicide movement are all over “Your Life, Your Choices.” Its authors are prominent figures in the movement and are on the record favoring assisted suicide and health care rationing.

9 and 10 Most prominently, lead author Dr. Robert Pearlman signed an amicus brief arguing in favor of assisted suicide in the landmark case of *Vacco v. Quill*, which originated in the State of New York and was decided by the U.S. Supreme Court. His legal brief argued “that the right to physician-assisted suicide should be recognized by this Court as a fundamental right.” Dr. Pearlman is entitled to his opinions, but his support of assisted suicide has found its way into VA policy and resources. In fact, the 2007 edition 11 of this supposedly even-handed and “mainstream” advance care planning guide lists only the Hemlock Society’s *Compassion & Choices* as a reference for advance directives.

8 *Fagerlin A, Schneider CE. Enough: The Failure of the Living Will. The Hastings Center Report, Vol 34, 2004.*

9 *Jecker NS, Peralman RA. Ethical Framework for Rationing Health Care. J Med Philos. 1992 Feb;17(1): 79-96.*

10 *Pearlman RA, Starks H. Why do People Seek Physician-Assisted Death? in Quill TE, Battin MP. Physician-Assisted Dying: The Case for Palliative Care & Patient Choice. Johns Hopkins University Press. 2004.*

11 *Pearlman R, Starks H, Cain K, Cole W, Rosengren D, Patrick D. Your Life, Your Choices: Planning for Future Medical Decisions. U.S. Department of Veterans Affairs. Second edition. June 11, 2007.*

A Bad, New Standard

The real danger “Your Life, Your Choices” poses is that if its approach to advance care planning and medical decision-making is deemed “mainstream” by bioethicists and other such experts, soon it will take hold and will be widely adopted as the standard across other health systems. This approach is in

direct contradiction to the dignified care provided by palliative care professionals, including many at VA hospices and medical centers. Thus, instead of you making health care decisions based on diagnosis of a terminal illness, the new standard will become “when is your life not worth living anymore?” This “right to die” will become a right these vulnerable groups will get first. Disability rights groups and others have long been suspicious of advance directives because they fear it will become a means to deny them care. They are not comforted when the VA guide casually asks them, “what does „being a vegetable“ mean to you?” Nor are they unconcerned when an American Medical Association ethicist asks them, as was stated in a recent newspaper story, to contemplate their “place in life.” It is not for the government or any piece of legislation to ask that question. The approach the VA is taking and the overreaching nature of the House legislation on advance care planning will reintroduce fear and suspicion and chill the very discussions they seek to encourage.

Conclusion

In conclusion, our main concern is that people remain the primary decision-makers in their care. We believe people should decide this issue for themselves, and that it should not only be left to bioethicists, lawyers and bureaucrats.

I would encourage every adult to talk with their doctor about advance care planning; and I would support public policies that encourage such discussion. It is wonderful that advance care planning is now discussed as part of the “Welcome to Medicare” consultation with a physician. That was a positive step forward that we supported. In the same fashion, we would support a simple provision that makes an advance care planning consultation reimbursable under Medicare. Patients should talk to their doctors about this. But the contents of the conversation should not be dictated by provisions of section 1233 of a health care affordability bill. And this federal legislation should not be used as a state mandate for the medical orders model, complete with the structure, policies, and implementation practices already decided. The issue is a small piece of the much bigger puzzle of health care reform. Still, the impact of this provision will have long and lasting implications on how we care for people near the end of life and how we talk about health care decision-making.

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Testimony

of

Joseph R. Baker III

President

Medicare Rights Center

before the

New York State Senate Committee on Aging

Senator Ruben Diaz, Sr., Chair

regarding

H.R. 3200:

**“America’s Affordable Health Choices Act of 2009” and Its Impact on Senior
Citizens**

September 8, 2009

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My name is Joe Baker and I am the President of the Medicare Rights Center. I would like to thank you Chairman Diaz and the other members of the New York State Senate Committee on Aging for calling this hearing to set forth the facts about the health reform proposals contained in H.R. 3200: “America’s Affordable Health Choices Act” and its impact on senior citizens. There has been a considerable effort to misinform and scare senior citizens into opposing health care reform, and your efforts to provide accurate information and informed debate are to be commended.

The Medicare Rights Center is a national, independent, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through individual counseling and advocacy, educational programs, and public policy initiatives. We provide services through six different hotlines to individuals, caregivers, and professionals who need answers to Medicare questions or help securing coverage and getting the health care they need. Our work with people with Medicare gives us a unique perspective on the current health reform debate.

Congress has been working to bring affordable health insurance to all Americans. H.R. 3200, which is the product of three committees in the House of Representatives—the Education and Labor Committee; the Energy and Commerce Committee; and the Ways and Means Committee—provides a number of improvements to Medicare coverage for older adults and people with disabilities. While there is a lot of talk about so-called “cuts” to Medicare, the untold story of reform is the approximately \$320 million that H.R. 3200 invests in Medicare.

There are three major ways in which this legislation will benefit people with Medicare. The legislation works to make prescription drugs more affordable, improves access to primary and preventive care and broadens access to benefits for people with Medicare who have low incomes.

First, the bill includes a gradual narrowing and eventual elimination of the “doughnut hole” or coverage gap in Part D prescription drug coverage. Narrowing this gap will begin in 2011. In addition, people who are in the doughnut hole will benefit from a new mandatory 50 percent discount on brand-name drugs required by the bill.

This provision will remove one of the concerns we hear most frequently through our work with people with Medicare—the high cost of prescription drugs during the Part D doughnut hole. Currently, over 3.4 million people with Medicare hit this Part D coverage gap each year and must pay the full price for their medicines. We frequently receive calls on our consumer hotlines from individuals who must skip doses, split their pills, or forgo medications altogether because of the high out-of-pocket costs of prescription drugs when they are in the doughnut hole.

Secondly, the bill makes a considerable investment in primary and preventive care, exactly the type of care that seniors and people with disabilities with Medicare need to be active members of their communities. People with Medicare will benefit from provisions that will remove obstacles, such as high out-of-pocket payments, that prevent them from accessing wellness and prevention services covered by Medicare.

The bill waives deductibles and cost-sharing for preventive benefits. For instance, Medicare currently covers 80 percent of the cost of a hepatitis B vaccine after the deductible is met, and the patient is responsible for the remaining 20 percent. HR 3200 would have Medicare cover the full cost, with no deductible. In fact, this bill helps to ensure that people with Medicare are able to get all necessary and federally recommended vaccines, including the relatively new shingles vaccine, by having Medicare Part B pay for them in full. Other preventive care, such as glaucoma screening and diabetes self-management training, would also be covered in full.

H.R. 3200 will also increase reimbursements to doctors who provide primary care, thereby offering them incentives to enter this practice area. The bill also provides incentives to those doctors or groups of doctors who provide a “medical home” to patients wherein they coordinate the care that those patients receive from a variety of providers. According to a 2006 MedPAC report, the average person with Medicare sees five doctors. However, there is no incentive in the current Medicare system for doctors or other care providers to talk with each other. We must often facilitate these conversations through our casework, or our clients must do so for themselves, which can be difficult, especially in times of acute illness. H.R. 3200 provides incentives to facilitate communication among a patient’s multiple caregivers.

Furthermore, the bill provides funding for comparative effectiveness research, which will help health care providers know which treatments are the most appropriate and successful for different conditions. An amendment to the bill addresses the concerns of those opposed to comparative effectiveness research; it specifically prohibits the government from denying care based on this research and prevents CMS from using research to deny coverage based on cost.

Finally, H.R. 3200 expands access to programs that help people with Medicare who have low incomes. Much of our organization’s work focuses on low-income people with Medicare. Currently, eligibility for assistance with drug costs through the low-income subsidy (LIS) and assistance with Part A and B cost-sharing and premiums through Medicare Savings Programs (MSP) is restricted by an asset test that penalizes low-income beneficiaries who have saved for their retirement. H.R. 3200 raises the asset threshold for both programs to \$17,000 for an individual and \$34,000 for a couple, allowing low-income

beneficiaries to maintain very modest nest eggs for their retirement. Due to your leadership, Senator Diaz, along with that of Governor Paterson and your fellow legislators, New York has gone a step further and eliminated the asset test entirely—opening this program to even more low-income seniors who are very much in need of this assistance.

Let me briefly address the issue of the so-called “cuts” that many opponents of the bill mention in trying to drum up opposition to it. These “cuts” are actually savings that providers like hospitals have already agreed can be made in order to trim Medicare’s budget and contribute to health care reform without affecting access to care for people with Medicare. To the extent that some providers disagree about the level of these savings, that is a legitimate debate that we can have, but all agree that they can contribute something. Secondly, and perhaps most importantly, there are no cuts to the actual benefits that seniors and people with disabilities with Medicare will actually receive, nor are there increased costs imposed upon them by this bill.

As you know, there is one specific section of HR 3200, Section 1233, the Advance Care Consultation provision, about which there has been a great deal of discussion, much of it misinformed or misleading. As an organization that is dedicated to helping older Americans and people with disabilities access comprehensive health care, it is troubling that a part of reform that will actually expand access to health care services for people with Medicare may be eliminated from the final bill because opponents have distorted its meaning in order to create fear among the public.

To be clear, the provision provides Medicare coverage for optional patient counseling concerning end-of-life care once every five years, or, if desired by the patient, more frequently, based on his or her changing health status. The benefit is completely voluntary, and any claims otherwise are false. The provision provides Medicare beneficiaries with access to a new, elective service—education and counseling—that is not currently available to them under the Medicare system.

Patients who wish to receive counseling would not be required to sign either an advance directive or an order for life-sustaining treatment. Orders for life-sustaining treatment will always be honored, and patients who wish to create these documents are given counsel and assistance in doing so. The legislation ensures that patients’ preferences—whether it is to end treatment or to continue receiving life-sustaining treatment, regardless of the circumstances—are respected and known to their caregivers. This provision does not change the current standard of care, which is to provide life-sustaining treatment unless the patient or the patient’s duly appointed representative has indicated otherwise.

In addition, payments to doctors are not based on the outcome of counseling. A doctor merely provides information—patients alone make decisions regarding life-sustaining treatments and the specific situations in which different options are to be pursued. That is perhaps the most important part of this program: educating people with Medicare about the treatment options available to them, while they are still able to make these assessments for themselves.

Health crises have a great and emotional impact on individuals and families; providing counseling will better prepare people with Medicare and their families for these crises and will help ensure that Medicare beneficiaries’ individual choices are respected. Oftentimes, these conversations happen too late, if at all, leaving patients and their families few choices and little time to make informed decisions about their own and their loved ones’ care. This provision recognizes the autonomy of people with Medicare, and allows them to control choices about the care they wish or do not wish to receive.

Too often, the debate concerning this provision focuses on a narrow, limited subject—whether someone desires life-sustaining treatment or not. But that debate misses a significant and important aspect of Section 1233. The provision addresses not only advance directives and the like, but also provides funding for counseling on the availability of care options such as palliative care and hospice, services paid for by Medicare that are underutilized, and also provides support for conversations about the settings in which patients would most like to receive care.

HR 3200 is not the first bill to include a provision that proposes to allow Medicare beneficiaries access to counseling on end-of-life care, or allowed for the use of orders for life-sustaining treatment. Many states have enacted or are developing similar initiatives at a local or statewide level, including New York.

When state law allows, as New York State law has for over 15 years, conversations covered by Section 1233 could include information about designating proxies or surrogates—someone such as a spouse or adult child, who the patient trusts to make decisions if he or she is unable to do so in a medical emergency. This is the furthest thing from giving the government control over your care.

And in 2008, Governor David Paterson signed into law a statewide expansion of a pilot program established in 2005 under Governor George Pataki, which allowed Medical Orders for Life Sustaining Treatment (MOLST) to be used instead of ‘do not resuscitate’ orders. The New York State Department of Health website states, “Honoring patient preferences is a critical element in providing quality end-of-life care. To enable physicians and other health care providers to discuss and convey a patient’s wishes regarding cardiopulmonary resuscitation (CPR) and life-sustaining treatment, the Department of Health has approved a physician order form, the Medical Orders for Life Sustaining Treatment (MOLST).”

In recent years, federal Medicare policy focused on the virtues of providing choice to beneficiaries and allowing people with Medicare to take control of their own care. This is the purpose of the Advance Care Consultation language. The provision attempts to preserve the independence of the doctor-patient relationship by allowing an individualized, thoughtful conversation among doctors, patients and patients’ families about treatment options in the most difficult times of people’s lives.

Many have sought to instill fear by arguing that Section 1233 puts us on a slippery slope that will lead to rationing of care or euthanasia. The same arguments were used against the legalization of health care proxies and other advance directives over the past decades, and yet we have not seen these disaster scenarios become reality.

In conclusion, HR 3200 contains many provisions that would benefit people with Medicare. The bill is long, it is technical, and it is nuanced, but this is an absolute necessity as we are dealing with issues that seriously impact people’s lives. And that is why getting the facts right is so important. Without accurate information we cannot have an honest debate. Playing on the fears of Medicare beneficiaries is inappropriate and disrespectful to the people we serve. Encouraging the dissemination of the correct information not only encourages meaningful debate, but also will lead to better benefits and health care for those most in need. Thank you for holding this hearing so that we can the facts out all work together to better the lives of those with Medicare.

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New York Senate

Aging Committee Hearing

H.R.3200

America's Affordable Health Choices Act of 2009
and Its Impact on Senior Citizens

Tuesday, September 8, 2009

250 Broadway

Manhattan, New York

Chairman Diaz and members of the Committee, thank you for inviting AARP to this timely discussion of health care reform and its impact on seniors. I am John Rother, executive vice president and director of policy and strategy at AARP. Today I am proud to represent our 40 million members at this hearing. That includes 2.6 million AARP members here in New York.

Few issues concern older Americans more than access to affordable, quality health care. Half our members are age 65 and over, and therefore eligible for Medicare. They want clear facts about what health reform would mean for them. AARP is devoting a great deal of resources to providing sound information about their important questions. We also are trying to address misunderstandings about health reform legislation.

One such misunderstanding is that Section 1233 of the House bill would create pressure to withhold care from older people, either directly or indirectly. It would create no such pressure. I will come back to this point later in my testimony.

AARP is fighting to ensure that seniors, working families and future generations have the health care they need when they retire. We have not endorsed comprehensive health reform legislation. We do, however, support key goals of reform, such as preserving the best aspects of our current system, targeting waste, covering more people and achieving smart savings that do not hurt individuals.

We believe that these goals, which would help both older Americans and the Medicare program, can be achieved through various legislative proposals.

AARP is fighting to make sure that health reform legislation achieves the following goals, while containing costs that are skyrocketing:

- **Protecting Medicare:** We want to make sure that seniors' benefits are not cut and in fact are strengthened. A better drug benefit is essential, and health reform would accomplish this by gradually closing the gap in coverage known as the doughnut hole. Proposed reforms also would attack waste and fraud, place more emphasis on prevention, aid low-income beneficiaries and improve coordination of care.
- **Protecting health care choices:** No one should interfere with treatment decisions made by doctors and patients, or require patients to change doctors. Proposed reforms in Congress are consistent with this principle.
- **Protecting consumers:** Provisions on the table would end discrimination by insurance companies. They would prohibit denials of coverage based on health history, a serious problem for people who are too young for Medicare. AARP also supports efforts to severely restrict the practice of age rating, by which insurance companies charge older customers much higher rates.
- **Protecting coverage people now have:** Proposals in both houses of Congress would give working-age individuals the security of knowing that if they lose or change jobs, they will be able to get affordable, quality health insurance.

The lack of insurance coverage can be fatal.

An Institute of Medicine study found that 20,000 people a year may lose their lives because they lack coverage.

While the exact number is subject to continuing research, virtually everyone agrees that a lack of coverage can create serious obstacles to needed care.

At AARP we hear the stories all the time: A man with cancer symptoms who delays his biopsy to save money; a small business owner who cannot afford a hip replacement; a woman whose husband is losing his eyesight -- and is going broke to pay the doctor. "There's nothing left for dental visits, eyeglasses or even new shoes," she told us.

People age 65 and over count on Medicare for their health coverage, and many are afraid of losing it. But a close look at the legislative proposals shows that Medicare could emerge from reform a stronger program with greater long-term financial stability. And it could do this while providing better care and holding down out-of-pocket costs.

Provisions in the House and Senate would provide immediate discounts to those who fall into the coverage gap in Medicare's Part D prescription drug program. Over time, they would fill the doughnut hole. This matters a lot, because the gap can cost beneficiaries almost \$3,500 a year, and it increases annually.

Proposed reforms also would make preventive services -- such as screenings for diabetes, osteoporosis and prostate cancer -- free to beneficiaries. Co-pays currently discourage many people from getting these screenings, which can prolong their lives.

Under H.R. 3200, Medicare would also strengthen its safety net for low-income beneficiaries. This would be achieved by eliminating the asset test that penalizes low-income people for saving money, and doing a better job of making sure individuals get the help they qualify for and need.

Some of the proposals are too technical to spark public interest, yet could be very helpful to patients. For example, reform proposals would begin to address the problem of avoidable readmissions to the hospital, which cost Medicare more than \$17 billion a year.

H.R. 3200 also provides more funding for doctors and nurses, which could improve the access of older patients to primary care. Proposed changes to doctors' payments would encourage primary care and better coordination of chronic illness. They also would help ensure that Medicare beneficiaries can keep the doctor of their choice or more easily find a doctor if they need to.

Funding to educate nurses also would increase, helping to address the looming nursing shortfall. And this is important: We not only have a shortage but we have a growing need. As our society ages and more individuals suffer from chronic conditions, the need for nurses will only increase.

The proposed savings for Medicare in H.R. 3200 have caused some misunderstanding. It's important to remember that done right, these savings could enhance the program. Current proposals correctly focus on savings achieved by reducing waste, fraud, excess profits to insurance companies and overpayments to providers. They do not reduce benefits covered by traditional Medicare or increase beneficiaries' out-of-pocket costs.

Older Americans also have expressed concern that health reform could lead to rationing of care. AARP would oppose any legislation that would restrict or ration care. There is absolutely nothing in the pending legislation that would cause care to be rationed for seniors – or anyone else. Health care reform would not give the government the power to make important health care decisions, for patients of ANY age. The fact is that by targeting and reducing waste and fraud in the system, we have the opportunity for big savings without restricting care.

Medical errors, duplicate tests, and lost records all drive up costs and hurt Medicare. AARP wants to make sure that tax dollars go to beneficiaries and are not squandered through waste.

Savings in H.R. 3200 are estimated to add five years of life to Medicare's Hospital Insurance Trust Fund, a real improvement in the financial stability of Medicare. Also, it's important to note that the total proposed net savings in Medicare amount to about 3% less in Medicare spending over the 10-year period. We believe that targeted measures can achieve 3% worth of smart savings in Medicare's budget, while still improving the program and strengthening benefits.

A balanced assessment of health reform and seniors should take all these improvements into account.

I would now like to address the concerns raised about Section 1233 of H.R. 3200. This is the provision that would allow seniors, if they choose, to have an advanced care planning consultation with their doctor, paid for by Medicare, once every five years (or more if the patient has a serious illness or significant change in their health).

AARP has listened carefully to the concerns raised by critics of this provision, and – with all due respect -- we believe they miss the point. Nothing in the legislation requires any conversations. Nothing in the legislation requires any action or any decisions.

Which is as it should be.

AARP would fiercely oppose any attempt to prevent doctors or hospitals from giving the best possible care to their patients. The House bill would not give government the power to make end-of-life decisions. Nor would a bill provide financial incentives for doctors to make unprofessional decisions about care their patients may need late in life.

AARP believes that cost should not be a factor in determining the most difficult, life-and-death decisions that we all may face one day. We recognize, however, that it can be helpful for people to plan for the future. Such planning may include deciding whether to have an advance directive and whether to name a close relative or other trusted person as proxy for health decisions.

Advance care planning allows patients to choose from a full range of options, to elect all life-sustaining interventions or to choose a palliative and comfort care approach.

We know that many of our members do not wish to leave these decisions to others, without providing guidance on their wishes and preferences. Too often, the physician is not aware of a patient's wishes when important decisions have to be made.

So there are some very important matters that people may want to consider, and many may find counseling useful.

But such doctor-patient conversations must be voluntary. That is clearly the case with this provision.

The view that doctors would face any penalty for NOT having such late-life conversations -- or that there is some sort of fine print that gives them an incentive to counsel patients to forego treatment -- is a misreading of the bill.

I'd like to get very specific here. The House legislation does call for developing new measures on end-of-life counseling -- among many others -- that doctors may choose to report to Medicare about how they treated a patient. Not only is reporting on these quality measures voluntary, the choice of which measures to report is voluntary too. And in fact, there is no

incentive or penalty for WHAT the doctor does; Medicare only provides small incentives for REPORTING what the doctor does -- or does not -- do.

Bottom line: There is no higher payment through the quality program for providing such counseling. This whole issue is based on misunderstanding a reporting option for doctors, among many other options.

Public confusion on this matter is unfortunate, because it has taken attention from serious problems that our country needs to address.

Our health care system costs too much, wastes too much, makes too many mistakes, and gives back too little value for our money. These problems affect Americans of all ages. AARP will continue to support common-sense reforms for health care, along with efforts to have a civil discussion about these important matters.

In closing, I'd like to point out that those of us who favor health reform have placed a big emphasis on cost savings, which the economy needs, of course. But I'd also like to say that the growing barriers to affordable care pose a moral issue for our society. AARP believes that all of us – doctors, hospitals, insurance companies and patients – share a responsibility to make the system better and to promote good health.

This civic duty comes right out of our shared Judeo-Christian tradition. Working together, debating this complex problem in a spirit of mutual respect, we believe we can achieve the right reforms that will make the system better for everyone.

Again, I wish to again thank the Chairman for the opportunity to testify.

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New York State Senate
Committee on Aging

Public Hearing on HR 3200:

America's Affordable Health Choices Act of 2009

Section 1233, Advance Care Planning Consultation

September 8, 2009

Presented by: Kathy A. McMahon
President and CEO

Hospice and Palliative Care Association of New York State

Thank you for the opportunity to address section 1233, Advance Care Planning Consultation of HR 3200, America's Affordable Health Choices Act of 2009. I am Kathy McMahon, President and CEO of the Hospice and Palliative Care Association of New York State. Our mission is to promote the availability and accessibility of quality hospice and palliative care for anyone in New York State confronted with life-limiting illness.

Although the Hospice and Palliative Care Association of New York State has not taken an official position on HR 3200, we have long supported the use of advance care planning to ensure a patient's choices are respected and honored. In recent months the term "advance care planning" appears to have been terribly mischaracterized. For in nearly everything we do...we plan in advance.

If you are taking a trip, for example, from Long Island to Buffalo, you would prepare yourself—you'd buy a map or go online to print step-by-step directions and a map or use your trusty GPS—But you'd have a plan. You'd choose the way you want to get there—highway or scenic route, toll roads or not, etc.

Your advance care plans—your living will, your health care proxy, your DNR—are your life plans, your road map for how you want to LIVE. For every moment of your life. No matter how seriously ill you become. To illustrate why these decisions are so important and why they need to be made in consultation with a patient's primary care or attending physician, let me share the story of Judy.

Judy was a breast cancer survivor. In November of last year she was diagnosed with cervical cancer. She had a team of wonderful oncologists whom she trusted implicitly; they had treated her when she beat breast cancer. Together they decided on an aggressive treatment plan. Judy had just a few specific goals or wishes as she faced this life-threatening situation. She wanted to attend and enjoy the May 2nd bridal shower she had so lovingly planned for her niece, Amy; and she wanted to be present at Amy's wedding on August 8th.

Judy completed her chemo in April and called her family to share the good news that she was cancer-free. She was jubilant, though still very tired and still suffering from a variety of troubling symptoms—all supposedly a result of the chemotherapy. The bridal shower arrived; Judy attended...but became ill during the event. Her symptoms—nausea, vomiting, diarrhea and pain—escalated and were not being managed. A month later Judy was told that the cervical cancer had metastasized to both lungs, her stomach, and groin. A family meeting was held and her oncologist said the cancer was not curable but it was treatable. Plans were made for her to go to a nursing home for rehabilitation with plans for her to start chemotherapy as soon as she was strong enough. But Judy did not regain her strength. She spent the next two months shuttling between several nursing homes for rehabilitation and the hospital for lengthy acute care stays to address escalating pain and symptoms, including blood clots. Attempts to get Judy home were not successful. Her last hospital stay was marked by great fear and frequent crying. Judy went to a nursing home on hospice care on August 12th. She died at 2:00 a.m. on August 20th.

Please think about Judy when you consider these points...About REAL advance care planning:

- The consultation provision in HR 3200 gives patients information that will help them make their own informed decisions about their care... It covers the broad spectrum of care and options available to patients when facing a life-limiting illness; The consultation is with the physician, physician assistant or nurse practitioner who is serving as the patient's primary care provider; Research has shown that patients and family caregivers enjoy a much higher quality of life when patients discuss all of their options for care with their physician.
- The advance care planning consultation would be VOLUNTARY. It is not required. It certainly is not coerced. The advance care planning consultation would be reimbursable under Medicare, just like any other existing Medicare consultation.
- Beneficiaries could elect to have the consultation once every 5 years or when they face significant change in their health status. The key points here are that these advance care planning consultations are VOLUNTARY ... and they offer people options; they give patients the FREEDOM to choose the care that is best for them and their loved ones.
- Advance care planning discussions before the patient finds him or herself in a medical crisis will help ensure that the patient gets the care he or she wants.
- One of the most frequent comments that hospice providers all across New York and all across the nation hear from family members is: "Why didn't we know about hospice sooner?" Hospice and palliative care are just two options that would be discussed in an advance care planning consultation.
- The irony here is that research published just last year by Stephen Connor, Ph.D., and colleagues, presented convincing proof that patients who elect hospice care actually tend to live longer than patients with the same diagnosis and the same acuity who don't elect hospice care.
- So, to set the record straight, advance care planning involves: Understanding your healthcare choices; Thinking about your choices in light of what is important to you, your family and the values you share; Talking about your decisions with your loved ones and your doctors; Writing down your plans in Advance Directives so they will be ready if needed.
- And it's important to remember that...

Your advance care plans and advance directives can be changed as your medical and/or personal situation or wishes change; Advance care planning is done over time and is not a single conversation; Decisions like these are always best considered before there is a health crisis;

Advance care planning is a gift to your family. When serious illness threatens, it allows families to spend precious moments with their loved one not fighting about what a patient who no longer can speak for himself/herself may or may not have wanted.

It's important to remember that advance care planning has absolutely NOTHING to do with limiting care. It's NOT about hastening death. It's NOT about taking choice away from the patient. It's NOT about saving money!

So think again about Judy. She did not have a conversation with her trusted doctors that outlined her options and would have empowered her to make informed decisions about her own care. And the result was that her care did not include hospital-based palliative care. And only included hospice care in the last week of her life. Until Judy went on hospice, her pain and symptoms were not aggressively managed. She suffered greatly—not just physically, but emotionally and spiritually as well. She did not get either of her final two wishes—to go home and to attend her niece's wedding. By not having an advance care planning consultation, Judy's care was limited, and she did not have any real choices. Her care was decided by what her insurance would cover.

My questions to you and your colleagues Senator Diaz are: Why shouldn't patients like Judy have their choices explained to them? Why shouldn't they have all the information they need to make thoughtful decisions about their lives? Why shouldn't they have the time to express what they want to their primary care provider?

Judy was not some faceless patient in a large academic medical center. Judy was my sister-in-law, the aunt who was so incredibly thoughtful and attentive to my son and daughter and two grandchildren. It absolutely breaks my heart that despite my many phone calls to Judy, family and social workers, and long-distance coaching, that Judy did not get a palliative care consultation (the hospital social worker didn't know what my brother-in-law was talking about) and when Judy did elect hospice care her organs were already shutting down. She did not go home; she did not go to Amy's wedding. The fact that we weren't able to honor her last two wishes haunts me today.

Now let me share the story of another patient, Mary. Dr. Diane Meier of Mt. Sinai Hospital and the Center to Advance Palliative Care in New York City has given me permission to share Mary's story. Mary was a 59-year-old New Yorker diagnosed with lung cancer and initially given 6-12 months to live. Under the care of an oncologist from NYU, Mary actually lived for five years and was able to maintain a good quality of life throughout that time. In the last 14 months of Mary's life, as her symptoms worsened, Dr. Meier provided palliative care—managing her pain and controlling other debilitating symptoms. Thanks to the compassionate care she received, Mary died at home in the company of her husband and daughter, under the care of one of New York's fine hospices. With only days left in Mary's life, Dr. Meier helped counsel Mary to refuse a last futile round of chemotherapy delivered directly into the brain that no one thought was likely to help her live longer or enjoy a better quality of life in the time she had left.

The stories of Judy and Mary help illustrate the importance of this issue. Given the wealth of resources available to us here in New York State, I was dismayed to see that

other highly qualified experts—Dr. Diane Meier, Dr. Patricia Bomba, Dr. Russell Portnoy, representatives from the Hastings Institute and the Center to Advance Palliative Care—were not invited to share their knowledge and experience with this committee and the people of New York.

In conclusion, it's worth emphasizing that the advance care planning consultation proposed in HR 3200 is voluntary. Advance care planning offers people options. Advance care planning gives patients the freedom to choose the care that is best for them and their loved ones. Advance care planning provides a roadmap for how you want to live, for every moment of your life, no matter how seriously ill you become. Research has shown that patients and family caregivers enjoy a much higher quality of life when patients discuss all of their options for care with their physicians. Research also demonstrates that patients who elect hospice care actually tend to live longer than patients with the same diagnosis and the same acuity who don't elect hospice care.

Thank you.

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RICHARD E. BARNES
Executive Director

**Testimony of the
New York State Catholic Conference**

**Presented by
Edward T. Mechmann, Esq.**

**Assistant Director, Family Life/Respect Life
Office
Archdiocese of New York**

**Before the
Senate Standing Committee on Aging**

**Regarding the
Impact of National Health Care Reform
(HR 3200)
on Senior Citizens**

September 8, 2009

Good afternoon. I am Edward T. Mechmann, Assistant Director of the Family Life/Respect Life Office of the Archdiocese of New York. I am here today to present testimony on behalf of the New York State Catholic Conference which represents Archbishop Timothy Dolan of the Archdiocese of New York together with the Catholic bishops of the seven dioceses of New York State in matters of public policy.

The Church's Health Care Experience

The Catholic Church's health care ministry represents the largest single not-for-profit provider sector in New York State, and provides approximately 10 percent of health care services statewide. The state's 28 Catholic hospitals and their 172 related clinics account for more than 300,000 admissions, more than 800,000 outpatient visits, and more than 600,000 emergency visits annually, and they employ more than 70,000 employees. Our 54 nursing homes care for more than 10,000 residents, including nearly 8,000 Medicaid residents. Our 22 Catholic-sponsored home care agencies and long-term home health care programs account for nearly 10 percent of home- and community-based services statewide, and our six Catholic-sponsored hospice programs account for more than 25 percent of hospice admissions statewide. Fidelis Care New York, the statewide Catholic health care plan, provides coverage to nearly 400,000 low- and moderate-income individuals in 46 counties across the state through the Medicaid Managed Care program, Family Health Plus, Child Health Plus, Managed Long-term Care, and Medicare plans.

Services in Catholic facilities run the gamut from advanced long-term care for children and adults, specialty cancer care, and palliative care in Manhattan; home care therapy for children with special needs on Long Island and the northern metro New York suburbs; advanced stroke and cardiac care in the Capital District; alcohol and substance abuse services for adolescents and adults, occupational therapy, dialysis, dental clinics, and adult day care in the Southern Tier; and prenatal and maternity home care in Western New York.

The Church's Position on Health Care Reform

It is from this experience that the Catholic Bishops are a credible voice on the issue of national health care reform. The bishops at both the state and national level have long held that “health care is a right”ⁱ and that it is “unacceptable that so many people do not have access to affordable health care.”ⁱⁱ They have also stated that “[a]ffordable and accessible health care is ... an urgent national priority.”ⁱⁱⁱ

In a recent letter to Congress on behalf of the United States Conference of Catholic Bishops, Rockville Centre Bishop William Murphy noted that “genuine health care reform that protects the life and dignity of all is a moral imperative and a vital national obligation.”^{iv} The right to health care flows directly from the sanctity of human life; health care is the very means by which human life is protected.

Bishop Murphy, the Chairman of the U.S. Bishops' Committee on Domestic Justice and Human Development, has offered Congress and the White House some basic criteria which the Church strongly believes are necessary in whatever health care reform plan moves forward. They are:

- a truly universal health policy with respect for human life and dignity;
- access for all with a special concern for the poor and inclusion of legal immigrants;
- pursuing the common good and preserving pluralism including freedom of conscience and variety of options; and
- restraining costs and applying them equitably across the spectrum of payers.

Chief among these principles is the first: a truly universal policy that respects human life and dignity. A society that does not ensure basic life-affirming health care for those in need is failing in its basic responsibility. That's why the Church is insistent that whatever health care reform plan is

ultimately enacted, it must serve and protect human life. It must not encourage euthanasia or discrimination through rationing, require funding for the destruction of human life, or include abortion as a so-called “benefit.” As Archbishop Dolan recently summed it up, that’s not health care, “that’s unhealthy care.”

Section 1233 of H.R. 3200

While the Church’s position on health care reform is multi-faceted and longstanding, for purposes of this hearing, and in conformity with the hearing notice, we confine our comments today to Section 1233 of the current House bill (H.R. 3200.)

Admittedly, this section of the bill regarding “advance care planning consultations” is difficult to understand because it references so many other sections of law and requires significant research into currently existing statutes. Some supporters of this provision say that it is intended to be a harmless mechanism to ensure that the elderly will have their wishes respected when they can no longer speak for themselves. Some opponents of the provision have called these consultations mandatory and label them “death panels.”

In and of themselves, we do not see consultations between health care practitioners and patients about advance directives and end-of-life care as negative or harmful. Indeed, throughout the debates in the New York State Legislature regarding our state’s own health care proxy law and the current family health care decision-making legislation, our Conference has been consistent in urging policies that facilitate a patient’s informed decision making about end-of-life care. We know from experience that difficult life and death decisions are made at the bedside every day. We know that decisions for incapacitated individuals will be made on behalf of those individuals by somebody, and we believe it is appropriate and necessary for the law to encourage education about end-of-life care.

We note that the provision in H.R. 3200 does not require an individual to have such a consultation or to accept any recommendation concerning provision, continuation, or termination of any treatment, nor does it require an individual to execute an advance directive.

Since 1990, federal law (The Patient Self-Determination Act) has required hospitals, nursing homes, hospice providers and other health agencies to routinely provide patients with information on advance directives at the time of admission. However, H.R. 3200 would, for the first time ever, **make advance care consultations reimbursable under Medicare**. The bill provides that a physician would be paid for the consult once every five years, **or more often if the patient's circumstances warrant**. This is where we believe caution is necessary.

In an era when Medicare spending in the final years of a person's life can be staggering, where funds in the general economy are shrinking, and the baby boomer generation is aging, it is possible that incentives for cost containment may be in tension with patients' wishes and best interests. It is possible that well-intentioned medical professionals will be influenced by insurance companies, Medicare and the government to subtly bring pressure on patients, particularly vulnerable elderly and disabled patients, to refuse treatment and "get out of the way."

As physicians conduct their own "cost-benefit" analysis with each patient, "quality of life" judgments will likely come into play and work their way into the advance care planning consultations which are reimbursed with taxpayer dollars. It is possible that vulnerable patients will be steered into foregoing lifesaving treatment if the cost-benefit ratio is too high.

The recent revelation of the U.S. Department of Veteran Affairs' end-of-life planning document called "Your Life, Your Choices" highlights the critical importance of the content of these "advance care planning consultations" and the materials the government will create to facilitate them. The document makes blatant attempts to steer vulnerable

individuals into believing their lives are not worth living. The document reportedly asks users to envision various scenarios and ask themselves if life would not be worth living if they were, for example, confined to a wheelchair, or living in a nursing home, or becoming a severe financial burden on their family.

Here in New York, legislation passed in 2008 authorized the development of a simplified advanced health care directive for use by individuals with developmental disabilities. It is our understanding that the State Office of Mental Retardation & Developmental Disabilities is currently developing such a form, and here, too, we urge caution. Some advocacy organizations, in their attempts to explain health care choices to the disabled population, may oversimplify terms and suggest to the developmentally disabled that their “quality of life” may not make their lives worth living.

We believe it is inappropriate for government to use either obvious or subtle techniques to pressure vulnerable populations to end their lives. We do not believe doctors should be given financial incentives to encourage the signing of a DNR, the withdrawal of nutrition and hydration, or a reduced level of medical care.

It is also possible that in states like Oregon and Washington which have legalized assisted suicide, “advance care planning consultations” will cover the option of suicide for the elderly and infirm. Concerns about such possibilities are heightened with the knowledge that the nation’s foremost advocacy organization for euthanasia and physician-assisted suicide, “Compassion and Choices” (formerly the Hemlock Society) is working tirelessly to support Section 1233 of HR 3200. The founder of the Hemlock Society, Derek Humphry, once wrote, “One must look at the realities of the increasing cost of health care in an aging society, because in the final analysis, economics, not the quest for broadened individual liberty or increased autonomy, will drive assisted suicide to the plateau of acceptable practice.”^v

Conclusion

The New York State Catholic Conference believes that no health care reform plan should provide financial incentives for the rationing of health care based on age or disability, expected length of life, cost considerations or arbitrary judgments about a patient's "quality of life." There must be no bias in government policies toward the withholding or withdrawing of care. No senior citizen, disabled or other vulnerable New Yorker should be made to feel they have a "duty to die" because they are a financial burden. No plan must pay for or promote euthanasia or physician-assisted suicide.

The Conference believes that Congressional leaders should be urged to include specific language in whatever health care reform bill moves forward to ensure that individuals' lives are protected, and that they are not required to accept recommendations on end-of-life care, nor execute advance directives as a condition of health care coverage.

Thank you for this opportunity to present testimony today.

^v United States Conference of Catholic Bishops, *Health and Health Care*, 1981.

^v Ibid., *Health Care for All!*, 2005.

^v Ibid., *Forming Consciences for Faithful Citizenship*, 2007.

^v Letter from Bishop William Murphy to U.S. Senate and Congress, July 17, 2009, available at <http://www.usccb.org/sdwp/national/2009-07-17-murphy-letter-congress.pdf>

^v "The Unspoken Argument" from Derek Humphry and Mary Clement, *Freedom to Die*, (1998), p314.

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**new york state
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Statement of the New York State Right to Life Committee

Delivered by Barbara Meara, Chairman

Mr. Chairman, the New York State Right to Life Committee appreciates the opportunity to testify before you today concerning the crucial issue of the impact of current proposals for health care restructuring on our senior citizens.

Let me begin by emphasizing that as a pro-life organization New York Right to Life believes that all Americans should be able to obtain life-saving medical treatment, food and fluids, and that ensuring access to adequate health insurance for all is certainly compatible with that objective. Indeed, over two years ago our parent organization, National Right to Life, put forth proposals demonstrating how it would be possible to achieve universal health insurance without putting senior citizens and others at risk of rationing and denial of life-saving care, proposals available on its website at www.nrlc.org.^v

In raising serious questions about H.R. 3200, the health care restructuring bill before the federal House of Representatives, we do not wish to be understood as opposing health care reform or extension of health insurance to those currently uninsured, but rather as emphasizing how important it is that health care reform be done in the right way. New York State Right to Life has always prided itself on its commitment to accuracy and fairness in its assessment of legislative proposals, a standard we intend to adhere to today. It would be very unfortunate if the de-bunking of exaggerated or inaccurate criticisms of H.R. 3200 were to obscure legitimate and accurate concerns about important aspects of the bill.

Advance Care Planning

One feature that has generated considerable controversy is Section 1233 and associated provisions that promote “advance care planning.” Specifically, Section 1233 provides for Medicare reimbursement for consultations about “advance care planning” between health care providers and their patients when they enter Medicare, every five years thereafter, and if they become seriously ill. Other provisions require private and public health care plans to give potential enrollees the option to establish advance directives and direct the Secretary of Health and Human Services to spearhead a public education campaign, toll-free telephone hotline, and

clearinghouse to promote advance directives and other advance care planning.

New York Right to Life strongly encourages the execution of a pro-life advance directive, the Will to Live.^v The theoretical notion of providing objective and accurate assistance to patients to involve them in treatment decision-making, if truly directed to helping patients to understand and communicate their beliefs and preferences related to their treatment options, and to decide with their health care provider what treatments are best for them based on their treatment options, scientific evidence, circumstances, beliefs, and preferences is unobjectionable

and even commendable.

The danger comes to the extent the proposed process in practice deviates from one that facilitates the incorporation of patient preferences and values into the medical plan and becomes a means of subtly or otherwise pressuring patients to agree to less treatment, or less expensive treatment. The emphasis many advocates place on the savings to be expected from implementation of such proposals heightens this concern. For example, Holly Prigerson of Boston's Dana Farber Cancer Institute has been quoted as saying, "We refer to the end-of-life discussion as the multimillion-dollar conversation because it is associated with shifting costs away from expensive . . . care like being on a ventilator in an ICU, to less costly comfort care...."^v

Indeed, a medical journal article of which Prigerson was lead author concluded that the mean cost of care was 35.7% less for patients who reported having end-of-life discussions, compared with patients who did not.^v A recent study published in the *Journal of the American Medical Association* similarly concluded, "[P]atients who reported having end-of-life discussions received less aggressive medical care and were more likely to receive hospice services for more than a week."^v

What is particularly disturbing about this "cost-savings" rationale for this provision of the bill is that it appears to follow President Obama's call this past spring for "a very difficult democratic conversation" about "those toward the end of their lives [who] are accounting for potentially 80 percent of the total health care bill out here."^v

The author and blogger Lee Siegel, a strong advocate of universal health care coverage, points out the problem:

For those of us who believe that the absence of universal health care is America's burning shame, the spectacle of opposition to Obama's health-care plan is Alice-in-Wonderland bewildering and also enraging but on one point the plan's critics are absolutely correct. One of the key ideas under end-of-life care is morally revolting.

....

The section, on page 425 of the bill, offers to pay once every five years for a voluntary, not mandatory, consultation with a doctor, who will not blatantly tell the patient how to end his or her life sooner, but will explain to the patient the set of options available at the end of life, including living wills, palliative care and hospice, life sustaining treatment, and all aspects of advance care planning, including, presumably, the decision to end one's life.

The shading in of human particulars is what makes this so unsettling. A doctor guided by a panel of experts who have decided that some treatments are futile will, in subtle ways, advance that point of view. Cass Sunstein ["who is Obama's nominee for regulatory czar"] calls this "nudging," which he characterizes as using various types of reinforcement techniques to "nudge" people's behavior in one direction or another. An elderly or sick person would be especially vulnerable to the sophisticated nudging of an authority figure like a doctor. Bad enough for such people who are lucky enough to be supported by family and friends. But what about the dying person who is all alone in the world and who has only the "consultant" to turn to and rely on? The heartlessness of such a scene is chilling.^v

Misuse of Comparative Effectiveness to Deny Treatment Based on Age or Disability

A second area of concern is the potential misuse of comparative effectiveness research. The House bill, as reported, allows comparative effectiveness research to be used in making coverage decisions, determining reimbursement rates, and in establishing incentive programs in ways that could discriminatorily deny or limit health care based on age, present or predicted disability, or expected length of life.

The premise of comparative effectiveness research is that determinations can be made about whether certain treatments are more effective than others in treating a given diagnosed condition. The problem lies in the standards used to determine what counts as "more effective." In the scholarly literature on such research, heavy reliance is placed on what are known as "quality-adjusted life years." As one medical journal article describes it, "The basic idea underlying the QALY [Quality-Adjusted-Life-Year] is simple: it assumes that a year of life lived in perfect health is worth 1 QALY (1 Year of Life × 1 Utility = 1 QALY) and that a year of life lived in a state of less than this perfect health is worth less than 1. . . . By moving away from a purely biological model . . . a need arises to focus on areas such as the individual's ability to operate in society [and] disability."^v Some measures have "negative . . . scores for health states perceived as being worse than death."^v

In a featured piece in the July 19 *New York Times Magazine*, Princeton bioethicist Peter

Singer openly advocated government rationing of health care, using QALYs. He made it clear that society should be more willing to withhold treatment from those who are old and those with disabilities.

“The death of a teenager is a greater tragedy than the death of an 85-year-old, and this should be reflected in our priorities,” he wrote. “[S]aving one teenager is equivalent to saving 14 85-year-olds.” Similarly, “If most would . . . choose 6 years of nondisabled life over 10 with quadriplegia, but have difficulty deciding between 5 years of nondisabled life over 10 with quadriplegia, then they are, in effect assessing life with quadriplegia as half as good as nondisabled life.”

In one example in the medical literature, an attempt was made to assess different quality adjusted life year scores for each of the following: “no physical disability, limp, walk with crutches, and need a wheelchair.”^v In another, the authors wrote, “[I]t may be judged that one year of life with a moderate disability is equivalent to 0.75 years of life at optimal health.”^v

The assumptions built into such a use of quality-adjusted life years are often inaccurate. As Hayden Bosworth of the Duke University Medical Center documents, “Patients who have not experienced a stroke . . . or individuals at risk for future stroke . . . respond with low [quality of life] estimates for physical impairments. Yet it is clear that patients who actually experience a high level of impairment as a result of a stroke provide high estimates of their quality of life.”^v

As part of the ongoing negotiations over the bill that may come out of the Senate Finance Committee, agreement has been reached on language to prevent discriminatory denial of treatment based on age or disability through the use of comparative effectiveness research.^v We strongly urge that this language be added to the House bill.

Over-Promising and Under-Funding

As I indicated at the beginning of my testimony, we are convinced that there are ways of ensuring adequate funding to cover extension of health insurance to the uninsured. Unfortunately, instead the House bill relies heavily on cuts in Medicare to fund this extension, effectively robbing Peter to pay Paul. It includes a net cut of \$200 billion over ten years.^v

In the words of Bruce Yarwood, President and CEO of the American Health Care Association, “The bottom line is that U.S. seniors’ Medicare-funded nursing care will be substantially undermined by the pending health reform bill in the U.S. House of Representatives Arguments being made that seniors’ benefits will not be reduced by the House bill ignore the fact that when Medicare cuts provider reimbursement, providers, in turn, are forced to cut staff because labor expenses comprise 70 percent of facility costs. Cutting staff within a facility,

has a direct, immediate, negative impact on patients and their care – and that is what the House bill will do.”^v

New York faces Medicare cuts in nursing care alone of 2.87 billion over ten years under the House bill.^v

The difficulty goes beyond the way the House bill relies on Medicare cuts to finance a large portion of funding health insurance for the uninsured. The revenue sources the House bill uses to make up the difference between the cost of the program and the cuts in Medicare, Medicaid, and the CHIP program will not cover the full cost in the future. Economist David Leonhardt points out the basic problem: “Over time, general taxes — taxes on income, for instance — don’t rise as quickly as health costs do. General taxes generally rise with economic growth, and these are the kind of taxes the House would use to pay for health reform. But health spending is growing much more quickly than the economy is.”^v

The dangerous consequence is that not too many years in the future, having over-promised and under-funded, the government will be faced with the choice of adding other means of revenue or, far more likely, in some way imposing rationing.

Thank you for the opportunity to present the views of the New York State Right to Life Committee on the House of Representatives health care reform bill.

v. <http://www.nrlc.org/MedEthics/SaveNotRation.html>

v. It is available on our website at <http://www.nysrighttolife.org/willtolive.htm> .

v. <http://www.oncologynursingnews.com/end-of-life-care-talks-better-for-patients-and-budgets/article/137327/>

v. “Health Care Costs in the Last Week of Life Associations With End-of-Life Conversations,” Arch Intern Med. 2009;169(5):480-488.

v. Wright AA, Zhang B, et al. Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment. JAMA. 2008;300(14):1665-1673.

v. April 14 interview, published in the New York Times Magazine April 29, 2009 <Available at <http://www.nytimes.com/2009/05/03/magazine/03Obama-t.html?pagewanted=all> >

v. www.thedailybeast.com/blogs-and-stories/2009-08-11/obamas-euthanasia-mistake/

v. Prieto, L, & Sacristan, J (2003). Problems and solutions in calculating quality-adjusted life years (QALYs). Health and Quality of Life Outcomes, 1, Retrieved June 17, 2009, from <http://hqlo.com/content/1/1/80>.

v. Vetter, T (2007).A primer on health-related quality of life in chronic pain medicine . Anesthesia & Analgesia, 104, 703, 711.

v. Duru, G, Auray, J P, Beresniak, A, Lamure, M, Paine, A, & Nicoloyannis, N (2002). Limitations of the methods used for calculating quality-adjusted-life-year values. Pharmacoeconomics, 20, 463-73.

v. A. Atherly, S.D. Cutler, E.R. Becker. “The Role of Cost Effectiveness Analysis in Health Care Evaluation,” The Quarterly Journal of Nuclear Medicine 2000 June; 44 (2): 112-120.

v. Bosworth, H (2001).Health-related quality of life after stroke: a comprehensive review. Stroke, 972.

v. The agreed language is:

“(1)The Secretary [of Health and Human Services] shall not use comparative effectiveness evidence in determining coverage, reimbursement or incentive programs for a treatment in ways that treat extending the life of an elderly, disabled, or terminally ill patient as of lower value than extending the life of a person who is younger, non-disabled, or not terminally ill.

“Rule of construction: This limitation shall not be construed to prevent the Secretary from using comparative effectiveness evidence in determining coverage, reimbursement or incentive programs based upon comparing the difference in the effectiveness of alternative treatments in extending a patient's life due to that patient's age, disability, or terminal illness.

“(2) The Secretary shall not use comparative effectiveness evidence in determining coverage, reimbursement, or incentive programs in ways that preclude, or with an intent to discourage, patients from choosing treatments based on how they value the tradeoffs between extending the length of their life and the risk of disability.

“Rule of Construction: This limitation shall not be construed to limit the application of differential copayments based on factors such as cost or type of service. Nothing in this legislation shall be construed to limit comparative effectiveness research or any other research, evaluation, or dissemination of information concerning the likelihood that a treatment will result in disability. In addition, this limitation shall not be construed to prevent the Secretary from using CE evidence in determining coverage, reimbursement or incentive programs based upon comparing the difference in the effectiveness of alternative treatments in extending a patient's life due to that patient's age, disability, or terminal illness.

“(3) The Institute shall not develop or employ a dollars per quality adjusted life year (or similar measure that discounts the value of a life because of a person’s disability) as a threshold to establish what healthcare is cost-effective or recommended. The Center for Medicare and Medicaid Services shall not utilize a dollars per quality adjusted life year (or similar measure that discounts the value of a life because of a person’s disability) as a threshold to determine coverage, reimbursement, or incentives programs.”

v. http://www.msnbc.msn.com/id/32225671/ns/politics-capitol_hill/

v. Quoted in “New Study: State-by-state Impact of Proposed Medicare Cuts to Skilled Nursing Facility Care for Seniors”, August 20, 2009 press release available at http://www.ahcancal.org/News/news_releases/Pages/StatebystateImpactofProposedSNFMedicareCuts.aspx .

v. Id.

v. David Leonhardt, "Health Care Reform: Beyond the First Decade" ; blog available at <http://economix.blogs.nytimes.com/2009/08/06/health-care-reform-beyond-the-first-decade/> . As he points out, "[T]he way to pay for an expansion of health insurance, over the long term, is to reduce health spending or to tax health spending." The first means rationing; the second is the alternative that would work, as explained at <http://www.nrlc.org/MedEthics/SaveNotRation.html> and in the webinar at <http://nrlcomm.wordpress.com/2009/06/13/hcrwebinar/>

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