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August 31, 2006

Patricia A. Maryland, Ph.D., Chair  
Citizens' Healthcare Working Group  
Agency for Healthcare Research and Quality  
Attn: Interim Recommendations  
7201 Wisconsin Ave., Rm. 575  
Bethesda, MD 20814

**By email:** [citizenshealth@ahrq.gov](mailto:citizenshealth@ahrq.gov)

Dear Dr. Maryland:

Thank you for this opportunity to comment on the interim recommendations of Citizens' Healthcare Working Group (Working Group). The Working Group provides an important opportunity for the public to come together and voice their concerns and their hopes for the future of our healthcare system. The Center for Medicare Advocacy, Inc. is encouraged by the public's overwhelming support for a universal healthcare system that provides access to healthcare for all, although it has concerns about whether the Working Group recommendations accurately reflect the views expressed in the community meetings and in online polls.

Since 1986, the Center for Medicare Advocacy (the Center) has provided education, legal assistance, and analysis, to help elders and people with disabilities obtain Medicare and necessary healthcare. The Center is a voice for a Medicare program universally available to all who contribute and in opposition to the privatization of healthcare. Its positions are based on the real life experiences of the thousands of individuals from around the nation who contact the Center for help.

The Center's writings, reports, positions papers and general advocacy frame a host of Medicare issues for policymakers and the media. Of particular concern to the Center are issues affecting people with chronic conditions, low-income Medicare beneficiaries, many of whom are dually eligible for Medicare and Medicaid, and those in need of long-term care.

The Center responds to over 6,000 calls and e-mails annually, represents individuals and classes in litigation, produces educational and self-help materials, pursues Medicare coverage for dually eligible beneficiaries, and provides legal support and training for the Multiple Sclerosis Society and

Connecticut's state health insurance and assistance program. The organization produces an array of written materials about Medicare, including the Medicare Handbook (now in its 7<sup>th</sup> edition) for Aspen Publishing Company (now Wolters Kluwer Law & Business), hosts two websites, and publishes electronic and hard copy newsletters. For more information about the Center, visit [www.medicareadvocacy.org](http://www.medicareadvocacy.org) and [www.fairmedicare.org](http://www.fairmedicare.org).

## COMMENTS

It is unclear why the interim recommendations were reordered in the revised draft released July 18, 2006. The Center supports prioritizing the recommendations as published in the first draft. Our comments reflect the ordering of recommendations as found in the first draft.

### **Working Group Recommendation:**

**It should be public policy that all Americans have affordable healthcare.**

**All Americans will have access to a set of core healthcare services. Financial assistance will be available to those who need it.**

*Americans should have a healthcare system where everyone participates, regardless of their financial resources or health status, with benefits that are sufficiently comprehensive to provide access to appropriate, high-quality care without endangering individual or family financial security.*

*Universal care.* The Center supports universal healthcare for all, modeled on a single payer system such as Medicare. This care should be accessible, equitable, affordable, and uniform, regardless of the recipient's health or financial status.

The overwhelming sense from the community meetings was that universal access to affordable healthcare is *the* number one priority to address in our healthcare system. The interim recommendations state that 94 percent of participants agreed with this statement, and online 92 percent agreed. It should therefore be listed as the first recommendation.

While there was not clear consensus on how to provide universal coverage, the interim recommendations show a strong preference for using variations of current systems to achieve this goal, including using fragmented private insurance markets and employer systems. Since most members of the public believe our current system is in a state of crisis, the recommendations should reflect this sense of crisis and urgency. In addition, the recommendations should reflect the group understanding that a universal healthcare benefit is needed, and that it should be simple to access and comprehensive in its scope, and administered through a single-payer, public system.

*Financing.* According to the interim recommendations, financing for universal care should be based on "fairness, efficiency, and shared responsibility." In making its arguments in support of fairness, efficiency, and shared responsibility, the recommendations should define what is meant by those terms. **Fairness** should mean that all people are asked to contribute a reasonably proportionate share

of their income toward a single payer. It does not mean that people who are sicker or have “unhealthy lifestyles” should pay more. **Efficient** financing would certainly *not* mean paying multiple insurers or giving tax credits to employers to attain universal coverage, but rather would mean contributing to a single payer system. Efficiency also refers to achieving cost savings through technology, but as the recommendations note, these savings are often hard to capture. A recent article in *Health Affairs* also shows that many improvements in technology, such as electronic medical records, do not result in cost savings. Finally, **shared responsibility** should mean that everyone pays into the same system. It should not mean that individuals have the undue burden of paying high deductibles for catastrophic plans, or disproportionate cost-sharing because they require more care. Cost sharing often becomes a barrier to accessing care for individuals with low incomes. Because people with low incomes are often sicker than the general population, it is especially important to assure equitable and affordable access to this population.

*Healthcare for all who contribute.* The Working Group, in all of its recommendations, discusses what kind of health system should be available to ‘Americans.’ This term is inappropriate as a universal system should provide care to all who contribute, regardless of citizenship status. The system should not discriminate against those who pay into the system but do not have full citizenship.

### **Working Group Recommendation:**

**Define a ‘core’ benefit package for all Americans.**

**Establish an independent non-partisan private-public group to identify and update recommendations for what would be covered under high-cost protection and core benefits.**

- **Members will be appointed through a process defined in law that includes citizens representing a broad spectrum of the population including, but not limited to, patients, providers, and payers, and staffed by experts.**
- **Identification of high cost and core benefits will be made through an independent, fair, transparent, and scientific process.**

**The set of core health services will go across the continuum of care throughout the lifespan.**

- **Healthcare encompasses wellness, preventive services, primary care, acute care, prescription drugs, patient education, treatment and management of health problems provided across a full range of inpatient and outpatient settings.**
  - **Health is defined to include physical, mental, and dental health.**
  - **Core benefits will be specified by taking into account evidence-based science and expert consensus regarding the medical effectiveness of treatments.**

*The selection committee.* The recommendation calls for a private-public group to determine what these benefits should be. This group will be comprised of patients, providers, *payers*, and experts. The public explicitly stated that they did not think employers and insurance companies should participate in these discussions, citing a frustration with barriers to access related to private health insurance. Patients are included in this group, but the prominence of their role must be clarified. For instance, the number of total members of the group must be defined, and the public and public interest groups should be allotted an established percentage of the seats.

*Core benefits.* Comments from the community meetings indicate that the public believes a wide range of benefits should be included in the ‘core’ benefit package, as noted in the recommendation. The Center supports having a broad range of benefits in this package, including primary care, preventive services, acute care, nursing home care, prescription drugs, management of chronic conditions, mental healthcare, eye and dental care, and care coordination.

*High-cost protection.* There is no indication from the community meetings that the general will is to use a combination of bare-bones benefits and high-deductible catastrophic coverage as an effective and affordable way to provide universal coverage. Inherent in this idea is the concept “donut hole” coverage, which is playing out in Medicare Part D right now. Moreover, the concept of a “donut hole” in Medicare Part D was primarily understood legislatively as a cost-savings measure to address budget limitations with respect to the amount of money to be made available (over a 10 year period) to fund the prescription drug benefit.

As proposed, catastrophic services would encompass a ‘core’ set of services, with no coverage between that set of core services and an undefined ‘catastrophic’ level of coverage. As our experience with Part D has shown, gaps of any kind in healthcare coverage result in disjointed care. People without coverage often cannot access the care they need, cut back on necessary services or go without care entirely, in order to save money. Savings here, though, are offset by higher use of other services such as emergency room care. The best solution is to provide comprehensive and uniform coverage for all, regardless of health or ability to pay, without gaps in covered care.

**Working Group Recommendation: Guarantee financial protection against very high healthcare costs.**

**No one in America should be impoverished by healthcare costs. Establish a national program (private or public) that ensures**

- **Coverage for all Americans,**
- **Protection against very high out-of-pocket medical costs for everyone, and**
- **Financial protection for low income individuals and families**

*Prioritizing affordable care for all.* The recommendation that individuals should have protection from very high out-of-pocket medical costs was moved from the third to the first in the revised interim recommendations, reflecting value in having high costs coverage, presumably through “high-deductible” plans, and supplemental coverage for low-income families, over a comprehensive benefit. This is entirely contrary to the spirit of the community meetings and the wish to have a comprehensive healthcare system. The Summary of Findings notes that:

- Individuals voiced support for a fairly comprehensive basic benefit design,
- Many were concerned about arbitrary limits on coverage and were not comfortable with bare-bones benefit packages,

Providing access to appropriate, high-quality care includes more than catastrophic coverage. It includes the benefits that cover all the areas encompassed in “healthcare wellness” listed in the second recommendation discussed above, including primary and preventive care, and acute care. In some cases, opinions were split on prioritizing high cost coverage above affordable care for all, pointing to the need for a combination of protection against everyday medical expenses *and* high cost care. The Center believes that no one should be impoverished by medical care. It is not, however, appropriate for members of the public to seek exorbitant insurance coverage for catastrophic care through the private insurance market, available in our current disjointed system, which this recommendation seems to support.

*Protection for low-income individuals.* The Center supports providing protection for low-income individuals. However, the vision of a universal healthcare system includes providing equal access to benefits for all. Such a system should not become one that is only for a particular income group, and many participants in the community meetings expressed concern about creating a system with different levels of care of different subsets of the population. It should be a system that protects everyone.

### **Working Group Recommendation:**

#### **Support integrated community health networks.**

**The federal government will lead a national initiative to develop and expand integrated public/private community networks of healthcare providers aimed at providing vulnerable populations, including low income and uninsured people, and people living in rural and underserved areas, with a source of high quality coordinated healthcare by:**

- **Identifying within the federal government the unit with specific responsibility for coordinating all federal efforts that support the healthcare safety net;**
- **Establishing a public-private group at the national level that is responsible for advising the federal government on the nation’s healthcare safety net’s performance and funding streams, conducting research on safety net issues, and identifying and disseminating best practices on an ongoing basis;**
- **Expanding and modifying the Federally Qualified Health Center concept to accommodate other community-based health centers and practices serving vulnerable populations; and**
- **Providing federal support for the development of integrated community health networks to strengthen the healthcare infrastructure at the local level, with a focus**

**on populations and localities where improved access to quality care is most needed.**

The Center supports the comments submitted by National Health Law Program regarding community health networks.

**Working Group Recommendation:**

**Promote efforts to improve quality of care and efficiency.**

**The federal government will expand and accelerate its use of the resources of its public programs for advancing the development and implementation of strategies to improve quality and efficiency while controlling costs across the entire healthcare system.**

- **Using federally-funded health programs such as Medicare, Medicaid, Community Health Centers, TRICARE, and the Veterans' Health Administration (VA), the federal government will promote:**
  - **Integrated healthcare systems built around evidence-based best practices;**
  - **Health information technologies and electronic medical record systems with special emphasis on their implementation in teaching hospitals and clinics where medical residents are trained and who work with underserved and uninsured populations;**
  - **Reduction of fraud and waste in administration and clinical practice;**
  - **Consumer-usable information about healthcare services that includes information on prices, cost-sharing, quality and efficiency, and benefits; and**
  - **Health education, patient-provider communication, and patient-centered care, disease prevention, and health promotion.**

*Evidence-based medicine.* The Center supports efforts to improve quality of care, recognizing the thousands die each year because of inappropriate care. While the public generally supported using evidence-based medicine as a means for defining benefits, the Working Group must define the term in its recommendations. In using evidence-based medicine standard, it should be recognized that evidenced-based medicine is constantly changing, and that much of the evidence we do have is in fact based on trials conducted on a narrow portion of the population – portions that often do not include minorities, the aged, or people with chronic conditions. Any evidenced-based practices policy should take this fact into consideration, and the provider's opinion should be given substantial weight when making coverage determinations.

*Quality improvement as cost savings.* Quality improvement is often a coded discussion for cutting

costs. While efforts to increase use of electronic medical records, to reduce fraud and waste, and to increase consumer educations are laudable goals that may improve quality, they may not help achieve costs savings. Significantly more savings could be achieved by focusing our efforts on creating a single payer, universal healthcare system. Indeed many at the community meetings cited simplifying administrative complexity as a way to reduce healthcare costs.

*Consumer information.* While it is important for patients to be able to receive as much information as desired when making healthcare decisions, consumer education is not the panacea for spiraling healthcare costs and low quality care. Furthermore, the data that is available to consumers and that is self-reported are not an accurate source of information. For instance, on Nursing Home Compare, facilities with multiple survey deficiencies and low staffing often have high quality marks. In addition, there is agreement on and use of so few quality indicators that it is difficult to get an accurate sense of a particular provider's quality of care.

Quality improvement efforts would be better directed toward more rigorous surveying and enforcing of existing laws and standards applicable to hospitals, nursing homes, physicians, and other providers. There should be serious consequences for those who provide poor quality care, including exclusion from Medicare and/or Medicaid, and significant financial penalties per identified violation.

#### **Working Group Recommendation:**

**Fundamentally restructure the way that palliative care, hospice care and other end-of-life services are financed and provided, so that people living with advanced incurable conditions have increased access to these services in the environment they choose.**

**Individuals nearing the end of life and their families need support from the healthcare system to understand their healthcare options, make their choices about care delivery known, and have those choices honored.**

- **Public and private payers should integrate evidence based science, expert consensus, and culturally sensitive end of life care models so that health services and community-based care can better deal with the clinical realities and actual needs of chronically and seriously ill patients of any age and their families.**
- **Public and private programs should support training for health professionals to emphasize proactive, individualized care planning and clear communication between providers, patients and their families.**
- **At the community level, funding should be made available for support services to assist individuals and families in accessing the kind of care they want for last days.**

Rather than restructuring palliative care and hospice, the Working Group should look to Medicare as a model for end-of-life care. The current Medicare hospice benefit is a program of palliative care..

It is available to Medicare beneficiaries with a medically diagnosed condition that is usually terminal within 6 months or less. One does not have to die within a given 6 month period, as persons can be entitled to multiple re-certification periods. Care can be provided in hospice stand-alone facilities, in nursing homes, or in one's home. More education about the broader use of hospice should be encouraged.

The Center would also emphasize the role of patient and family choice in making decisions about how to receive such care. More extensive care should not be denied because it does not fit within a palliative care model, nor should more extensive efforts be made for individuals with higher income while offering more palliative services to those with lower-incomes.

Respectfully submitted,

A handwritten signature in cursive script that reads "Jacqueline A. Bender". The signature is written in black ink and is positioned below the text "Respectfully submitted,".

Jacqueline A. Bender  
Project Analyst