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November 2006

Ethical Issues: Recommendations of the Citizens' Health Care Working Group

There is an important update regarding legislative attempts to improve health care, including end of life care, for all Americans in the this week's *Update* of the Missouri Hospice & Palliative Care Association (MHPCA).ⁱ In 2003 the U.S. Congress created the Citizens' Health Care Working Group.ⁱⁱ This group was charged with the task of facilitating a nationwide public debate about improving the health care system to enable universal access to quality and affordable health care coverage in this country, and for developing an action plan for Congress and the President to consider as they work to improve health care for all Americans. The 15-member group has issued its first set of recommendations in a report titled *Health Care That Works for All Americans*.ⁱⁱⁱ

The report came out of the Group's discussions with the American public around four questions: 1) What health care benefits and services should be provided? 2) How does the American public want health care delivered? 3) How should health care coverage be financed? 4) What trade-offs are the American public willing to make in either benefits or financing to ensure access to affordable, high-quality health care coverage and services? Interim recommendations were released earlier this year for public comment and the final recommendations were sent to Congress and the President in late September 2006.

The Group made six recommendations:

1. Establish public policy that all Americans have affordable health care.
2. Guarantee financial protection against very high health care costs.
3. Foster innovative integrated community health networks.
4. Define core benefits and services for all Americans.
5. Promote efforts to improve quality of care and efficiency.
6. Fundamentally restructure the way end-of-life services are financed and provided.

The last recommendation, which addresses end of life care, has three parts:

1. Public and private payers should integrate evidence-based science, expert consensus, linguistically appropriate and culturally sensitive end-of-life care models so that health services and community based care can better handle the clinical realities and actual needs of patients of any age and their families.
2. Public and private programs should develop and support training for health care professionals that emphasizes proactive, individualized care planning and clear communication between providers, patients and their families.
3. At the community level, funding should be made available for support services, including nonmedical services, to assist individuals and families in accessing the kind of care they want for the last days of their lives.

The Working Group also recommends two areas for consideration beyond the health care system. One is the need for more attention to be given to both paid formal (professional) and unpaid informal (family) caregivers. The report iterates that as the number of elderly Americans increases in this country, and as more caregiver services are required, the health care system will need to offer better compensation, improvements in training, and opportunities for professional growth in order to meet the increasing demand of and on caregivers. The second challenge encourages us to evaluate and learn from what we are doing by calling for the development and use of standardized instruments for collecting demographic, epidemiological, and clinical information, careful evaluation of emerging care models, and the dissemination of best practices.

Specific to end of life care, the report recommends that Medicare reimbursement for hospice services needs to better account for the most common patterns of death and dying while accommodating the differing trajectories of common causes of death. The report also argues that payment for providers needs to be less procedure-driven and more geared to the evaluation and management of complex cases, taking into account essential time-intensive services such as provider-patient counseling, guidance, and treatment decision-making. The report also calls for new models of care delivery and mechanisms to support terminally ill newborns and their families.

This report is very timely aid as we attempt to identify and implement interventions needed in the years to come that will effectively serve the health care needs of all citizens in this country. Especially for the growing numbers of most vulnerable, the aging and dying, and others who require complex means of care and support, this initiative will require a team effort from policy makers to the bedside if this initiative is to be successful.

ⁱ MHPCA Update 11-17-06

ⁱⁱ Citizens' Health Care Working Group Website: www.citizenshealthcare.gov.

ⁱⁱⁱ *Health Care That Works for All Americans:*

<http://www.citizenshealthcare.gov/recommendations/recommendations.pdf>.