

August 23, 2006

Citizens' Health Care Working Group
7201 Wisconsin Avenue, Room 575
Bethesda, Maryland 20814

Re: Comments on Interim Recommendations

To the Citizens' Health Care Working Group:

The National Health Law Program (NHeLP) submits these comments in response to the Interim Recommendations that the Citizens' Health Care Working Group (WG) issued on June 1, 2006 and updated on July 18, 2006. NHeLP is a national public interest law firm that seeks to improve health care for America's working and unemployed poor, minorities, the elderly, and people with disabilities. NHeLP serves legal services programs, community-based organizations, the private bar, providers, and individuals who work to preserve a health care safety net for the millions of uninsured or underinsured low-income people. Established over 35 years ago, NHeLP's areas of expertise include Medicaid and the State Children's Health Insurance Program (SCHIP); civil rights; linguistic access and cultural competency of health care; reproductive health access; and racial and ethnic health disparities. We have reviewed the Interim Recommendations in light of our expertise to assess how they would impact low-income individuals in the above-mentioned areas.

We appreciate the opportunity to comment on the Interim Recommendations and hope the Working Group will seriously consider our suggestions. Our comments are divided into three parts. Part I sets forth general comments on the recommendations. Part II details our comments on the WG's statement of values and principles. Part III includes our comments on each of the six recommendations.

I. GENERAL COMMENTS

A. Provide Further Clarity, Detail, and Consistency to the *Values and Principles* and to the Recommendations.

1. *Clarify the Values and Principles to create a stronger framework for the recommendations.*

We agree with many of the values that the WG has identified. Indeed, as the *Preamble* recognizes, Congress designed the WG, in part, to identify the "overarching values and aspirations" that constitute the heart of the health care system. Because the recommendations build on the *Values and Principles*, it is vital that the WG clarify them to create a more coherent foundation for the recommendations.

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2. *Further detail the execution of the recommendations.*

The WG should also provide more details on its plans to execute the recommendations. Generally, the recommendations lack a clear explanation of the financing and implementation mechanisms. We have highlighted the various areas in which the WG should further articulate its vision, which is necessary to understand the recommendations' impact on all Americans – particularly low-income individuals.

3. *Resolve the potential inconsistencies between the “medically effective” and “evidence-based” terminologies.*

Throughout the *Values and Principles* and the recommendations on benefits, quality and efficiency, and end-of-life care, the WG uses various forms of the terms “medically effective” and “evidence-based.” For instance, the WG seems to use the phrases “effectiveness of treatments” and “medically effective” interchangeably. Similarly, the WG refers to “evidence-based science,” “evidence-based medicine,” “evidence-based best practices,” and “medical evidence” without defining these terms. If the terms “effectiveness of treatments” and “medically effective” are the same, then the WG should select one and define it. Similarly, if the various forms of the “evidence-based” terms are the same, then the WG should choose one of the terms to use consistently and define it. If the terms do have different meanings, the WG should define each term and explain how it differs from the others. As we explain in Part III.B.3 regarding coverage of benefits, we suggest the WG broadly define the standards based on these terms.

RECOMMENDATION: Clarify the *Values and Principles* and explain how the recommendations will be implemented. Resolve the potential inconsistencies between the “medically effective” and “evidence based” terminologies and define the resulting terms.

B. Replace All References to “Citizens” With “Americans” to Reflect That the Recommendations Address Health Care for Immigrants.

The WG should consistently refer to “Americans” instead of “citizens” to reflect that the recommendations address *all* Americans, which the WG should define to include immigrants. Currently, the Working Group seems to use the terms “citizens” and “Americans” interchangeably, but the latter term is more consistent with the WG’s mission. Indeed, Congress called “for a *nationwide* public debate...to provide *every American* with...quality, affordable health care coverage,”¹ which strongly suggests the inclusion of immigrants in both the process and the result.

1. *Immigrants financially contribute to society and are not a fiscal burden.*

Non-citizen immigrants, like citizens, pay taxes to federal, state, and local governments. These include income taxes, sales and property taxes, and the full range of license and user fees.² An

¹ Medicare Prescription Drug, Improvement and Modernization Act of 2003, Pub. L. No. 108-173, § 1014(b)(1), 117 Stat. 2066, 2442 (2003) (emphasis added).

² Shikha Dalmia, Editorial, *Immigrants Pay Their Way*, Monterey County Herald, May 1, 2006. Even two-thirds of undocumented immigrants pay Medicare, Social Security and income taxes. Dalmia, *Immigrants Pay Their Way*.

immigrant and his or her future descendants contribute, on average, \$80,000 more in taxes than they will receive in public benefits.³ Nor do immigrants disproportionately use high cost health care such as emergency departments. A recent study found that the “communities with the highest levels of [emergency department] use did not necessarily have the highest numbers of uninsured, low-income, racial/ethnic minority, or immigrant residents.” Indeed, immigrants “had much lower [emergency room] use than citizens.”⁴ Because immigrants are contributing taxpayers, the recommendations must treat them as stakeholders in the health care system. Thus, we urge the Working Group to clarify that its recommendations apply to all Americans, not just citizens.

2. *Including immigrants is necessary to achieve health care for all.*

Any system for providing quality, affordable health care for all Americans cannot ignore immigrants – a sizeable segment of the American population. For instance, the WG designed its recommendations on affordability and benefits to reduce the number of, and fiscal burden on, the uninsured. Indeed, the uninsured pass on their cost of care to two main groups: (1) to consumers who absorb those costs by paying higher premiums for private insurance and (2) to taxpayers who pay the costs of the uninsured’s care through the funding of government programs.⁵ Because immigrants, relative to other sub-populations, are “more likely to be uninsured over an entire year,”⁶ solutions that do not insure immigrants probably would diminish any progress toward reducing the negative fiscal impact of the uninsured.

Furthermore, from a public health perspective, ensuring that immigrants have access to preventive and emergency care is imperative. For instance, restricting immigrant children’s access to immunizations could make those children more susceptible to disease, thus jeopardizing the health of other people who are not immunized. Similarly, restricting immigrants’ access to treatment during an emergency epidemic, such as the bird flu, would stymie efforts to curtail transmittal of the disease. Therefore, the WG should clarify that its recommendations apply to immigrants because addressing immigrants’ health care needs is essential to achieving the larger goal of health care for all.

RECOMMENDATION: Replace all references to “citizens” with “Americans” and define Americans to include immigrants.

II. COMMENTS ON STATEMENT OF VALUES AND PRINCIPLES

A. State That Health Is a Human Right.

Although we strongly agree that “[h]ealth and health care are fundamental to the well-being and security of the American people,” we recommend that the WG refine this concept to recognize

³ Panel on the Demographic and Economic Impacts of Immigration et al., *The New Americans: Economic, Demographic, and Fiscal Effects of Immigration* 334 (James P. Smight & Barry Edmonston eds., 1997), <http://darwin.nap.edu/books/0309063566/html>.

⁴ Peter J. Cunningham, *What Accounts for Differences In The Use of Hospital Emergency Departments Across U.S. Communities?*, *Health Affairs*, W324-336 (2006).

⁵ Families USA, *Paying a Premium: The Added Cost of Care for the Uninsured* (2005), http://www.familiesusa.org/assets/pdfs/Paying_a_Premium731e.pdf

⁶ Citizens’ Health Care Working Group, *The Health Report to the American People* (2005), at 16.

explicitly that health care is a human right. This signifies that each individual should be able to attain the highest standard of physical and mental health regardless of factors such as income, race, disability, and citizenship. Indeed, the WG implicitly recognizes this right in its statement of principles, which proposes that health care benefits should be available “independent of health status, working status, age, income, or other categorical factors....” An explicit statement of health care as a human right is needed, however, to expand the notion of health care from what we choose to provide as a nation to what we are obligated to provide. Because the Interim Recommendations seek to reduce cost and other barriers that interfere with one’s right to health, an explicit statement of health as a human right serves as a stronger foundation for the recommendations.

Additionally, recognizing health as a human right will align our nation more closely with the rest of the international community. Health as a human right is one of the principles upon which the constitution of the World Health Organization (“WHO”) rests,⁷ and the United States has accepted the WHO Constitution by its membership.⁸ Since the 1946 ratification of WHO’s Constitution, this right has been included in a series of international and regional human rights treaties, as well as in over 100 constitutions worldwide.⁹ Thus, acknowledging that health care is a human right is consistent with an international consensus and recognizes the reality that fundamental human rights are at stake in everyday health care decisions.

RECOMMENDATION: State that health is a human right.

B. Clarify the Concept of “Shared Social Responsibility.”

1. Low-income individuals already “contribute” through their existing tax burdens.

The WG should describe what it means when it says that people have a responsibility “to contribute.” This principle, which likely suggests different concepts to different people, is especially significant because it serves as the basis for the type of financial strategies that the WG recommends. All Americans financially contribute to society. While the more affluent often contribute a higher amount of money through the taxes they pay, lower income Americans likely contribute a higher percentage of their income because of the regressive nature of many taxes, such as the sales and property taxes. Thus we urge the WG to recognize the existing contributions of low-income individuals and not add new financial expectations.

2. Health care spending should not be balanced against other spending obligations.

The WG states that shared social responsibility includes considering health care spending “in the context of other societal needs and responsibilities.” To the extent this principle seeks to promote the efficient use of health care resources, it is unobjectionable. But we disagree that human health should be considered some sort of discretionary spending to be fit within the family budget. Rather, because health is a human right, we as a nation must spend what is necessary to attain the

⁷ Constitution of the World Health Organization, <http://www.who.int/governance/en/>.

⁸ World Health Organization, Countries, <http://www.who.int/countries/en/>.

⁹ Paul Hunt, Preface to *Human Rights and Human Welfare Review Digest*, <http://www.du.edu/gsis/hrhw/digest/health/index.html>.

highest standard of physical and mental health for everyone. As with justice, health must be a cornerstone of this country's foundation, whatever the cost.

If, however, the WG maintains that our nation should balance health care spending with other needs, then the WG should provide a fuller discussion of this and how it would affect low-income people. Any limits should not result in less access for or greater financial contributions from low-income individuals. Until the WG provides more detail, however, we cannot evaluate how balancing health care spending with other needs will impact lower income Americans.

RECOMMENDATION: Eliminate the suggestion that health care spending is discretionary and adopt the principle that we should spend what is necessary to attain the highest standard of health for everyone. If the WG maintains limitations on health care spending or suggests new taxes, clarify that these will not result in greater financial expectations for low-income people.

C. Replace All References to Limiting Coverage for Services With the Principle That All Low-Income Individuals Will Have Access to Medically Necessary Services At No Cost.

1. "Core" Benefits Become The Only Benefits for Low-Income Individuals

The WG implies a limit on the coverage of services by recommending a definition of a core benefit package. Defining a core benefit package assumes that some services would not be covered, presumably causing people to pay out-of-pocket to obtain them. While such an approach may be viable for people with disposable incomes, it will not work at all for the low-income community.

Instead, as we will elaborate in our comments regarding benefits, we recommend adopting a principle whereby all low-income people would have access to all medically necessary services at no cost. If deemed financially necessary (although we are not making this recommendation), higher-income individuals could be offered a more limited benefit package because they are likely to be able to afford the uncovered services out-of-pocket. At a minimum, "low-income people" should include all people with incomes at or below 200% of the federal poverty level ("FPL"), which is \$40,000 for a family of four in 2006.¹⁰ Of course, even families with incomes at and above 200% of poverty struggle to pay for health care expenses. For instance, the average annual premium for employment-based health insurance in 2005 was \$11,000, which is over one-fourth of a family's income at 200% FPL and almost one-fifth of a family's income at 300% FPL.¹¹ This suggestion is the most consistent with the public's stated desire for the most comprehensive coverage possible.¹²

¹⁰ Annual Update of the HHS Poverty Guidelines, 71 Fed. Reg. 3848, 3848-49 (Jan. 24, 2006), <http://www.aspe.hhs.gov/poverty/06fedreg.htm>.

¹¹ Kaiser Family Foundation, Employee Health Benefits: 2005 Annual Survey 7 (2005), <http://www.kff.org/insurance/7315/upload/7315.pdf>.

¹² Citizens' Health Care Working Group, *Dialogue With the American People*, at 10.

2. *Clarify That The “Right Care At The Right Time” Means, For Low-Income People, Receiving Medically Necessary Services At No Cost.*

The WG defines “access to care” as receiving “the right care at the right time,” but does not describe who will determine what care is “right” or when it is needed. Leaving this phrase undefined could harm low-income people who may need a certain health service that is not covered in the core package. The WG should explain that for low-income people, “the right care” refers to all medically necessary care (as defined by the person’s doctor or care giver) at no cost, and “the right time” refers to obtaining the service without delay. Thus, the WG should define health care access for low-income people more broadly by allowing them to receive, without delay, all medically necessary services at no cost.

RECOMMENDATION: Replace all references to a set of defined or core health services. Replace these references with the principle that all low-income individuals will have access to medically necessary services at no cost. Clarify that the “right care at the right time” means, for low-income people, receiving medically necessary services at no cost without delay.

D. Explain any Differences Between “Defined Set of Benefits” and “Set of Core Health Services.”

As we explained above, we disagree with limiting coverage of health services. However, if the WG maintains the notion of limited coverage in its final recommendations, then we recommend that the WG define and clarify the terminology it has chosen. It is unclear whether the concept of a “defined set of benefits” is the same as the “set of core health care services.” Is the WG using “benefits” and “services” interchangeably? If these concepts are different, the WG should explain the differences and define each concept. If these concepts are the same, the WG should use one concept consistently and define it.

Nor does the WG discuss what type of benefits the law will guarantee or whether federal, state, or local law would guarantee benefits by statute or regulation. Instead, the WG focuses on the “set of core health services” that an independent group would define on an ongoing basis. If the WG sees the independent group as establishing or recommending the benefits that will be guaranteed by law, it should say so. We would oppose any other arrangement. However, if the WG envisions a different arrangement, then it should further clarify that process.

RECOMMENDATION: If the WG maintains the concept of limiting benefits, explain any differences between the “defined set of benefits” and the “set of core health services.” Clarify that the envisioned benefits would be legally guaranteed.

E. Do Not Link the Coverage of Health Services to Health Status or Behavior.

The WG implies that cost sharing and access to benefits could be a function of health status or behavior by stating “individuals should be...good stewards of their health and health care resources.” This suggestion is inconsistent with the concept that health care should be provided independent of

categorical factors. The health care system should not be used to reward or punish individuals for having a particular health status or for engaging in certain behaviors. Doing so is not only ineffective, it is hypocritical in a country that spends billions of advertising dollars each year to promote the same bad habits that the health care system would punish.

1. Linking Health Care Access To Health Status Or Behavior Does Not Provide Any Benefits.

We are concerned about the potential detrimental effects if the WG maintains the position that cost sharing and access to benefits could be linked to health status or behavior. No studies show that that making access to health care conditional on a promise to stay healthy actually improves people's behaviors, creates health care savings, or leads to better health outcomes. To the contrary, common sense suggests that limiting access to needed care for people who, for whatever reason, have already made poor health choices is likely to lead to poorer health outcomes. It will also predictably result in the use of higher cost health care because of the delay in providing care.¹³ Thus, linking coverage of services to one's health status or behavior could harm individuals' health and increase health care costs.

2. Linking health care access to health status or behavior threatens the patient-doctor relationship.

Further, linking coverage of services to health status or behavior could jeopardize the patient-doctor relationship. Doctors, who would presumably have to report noncompliant patients, would be put in the role of enforcers. Such a situation would inherently undermine vital aspects of the patient-doctor relationship, such as trust, confidentiality, and candor. Because of the probable negative implications of this policy, the WG should clarify that it will not condition coverage of services on an individual's health status or behavior.

RECOMMENDATION: Clarify that coverage of health services will not be linked to health status or behavior.

F. Add “Quality” to the Principle Guaranteeing Affordability to Ensure Meaningful Coverage.

While we strongly agree that all Americans should have affordable health care, we recommend that the WG augment this principle by connecting affordability with quality. Affordable coverage may be meaningless if it is of insufficient scope or quality. Indeed, Congress recognized that meaningful health care reform could not isolate issues of affordability; Congress asked for solutions on providing Americans with “*quality*, affordable health care coverage.”¹⁴ Thus, including the word “quality” provides a stronger foundation for the recommendations by signifying that issues of affordability and quality are intricately linked.

¹³ Solomon, <http://www.cbpp.org/5-31-06health.pdf>.

¹⁴ Medicare Prescription Drug, Improvement and Modernization Act of 2003, Pub. L. No. 108-173, § 1014(b)(1), 117 Stat. 2066, 2442 (2003) (emphasis added).

RECOMMENDATION: Add “quality” to the principle of affordability to guarantee “quality, affordable health care coverage.”

III. COMMENTS ON THE INDIVIDUAL RECOMMENDATIONS

A. Working Group Recommendation: It Should Be Public Policy That All Americans Have Affordable Health Care.

1. *Define “Affordable Health Care” By Recognizing That Any Cost sharing For Low-Income People Limits Their Access to Needed Care.*

a. *Any cost sharing makes health care unaffordable for low-income people.*

NHeLP agrees with the concept of affordability. A Commonwealth Fund survey released on August 17, 2006 found that forty-eight percent of adults in households with gross annual income of \$35,000 to \$50,000 reported serious problems paying for health care and health insurance; while one-third of adults with family incomes between \$50,000 and \$75,000 a year, and one-fifth with incomes over \$75,000, reported serious problems with medical bills.

Affordability, however, has different meanings for different groups of people. Because the WG envisions a health care system in which everyone participates, and because the WG implies that everyone will pay something for health care regardless of income, this system could jeopardize health care access for low-income people who could not afford to participate. Study after study has demonstrated that even small amounts of required cost sharing discourage necessary use by low-income individuals who simply do not have disposable income available for that purpose.¹⁵ For example, a study published in the *Journal of the American Medical Association*, examined the consequences of imposing copayments for prescription drugs on adults receiving welfare. The copayments led to filling fewer prescriptions for essential medications, an 88 percent increase in the occurrence of adverse events (including death, hospitalization and nursing home admissions) and a 78 percent increase in emergency room use.¹⁶

Cost sharing requirements have a greater adverse effect on low-income people than on middle and high-income people. The RAND Health Insurance Experiment study found that requiring people with incomes below 200% FPL (\$40,000 for a family of four in 2006)¹⁷ to pay co-payments deterred a much higher percentage of them from seeking essential, effective than was the case for middle or high-income people with co-payments. Unlike with middle- and upper-income people, co-payments led to poorer health for those with low incomes. Among low-income adults and children, health status

¹⁵ See, e.g., Robyn Tamblyn, et al., *Adverse Events Associated with Prescription Drug Cost sharing among Poor and Elderly Persons*, *Journal of the American Medical Association*, 285(4): 421-429, January 2001 (revealing the detrimental effects of a Quebec policy that imposed copayments for prescription drugs on low-income adults); Joseph Newhouse, *Free For All? Lessons from the Rand Health Insurance Experiment*, Cambridge: Harvard University Press, 1996 (describing the RAND study’s findings that copayments reduced low-income people’s effective medical care).

¹⁶ Tamblyn, *supra* note 16.

¹⁷ Poverty Guidelines, <http://www.aspe.hhs.gov/poverty/06fedreg.htm>.

was considerably worse for those who had to make copayments than for those who did not.¹⁸ In fact, imposing even nominal cost sharing requirements harms low-income people's access to care. For instance, a study of four states' experiences with charging premiums in Medicaid – a program by design serving only low-income individuals – revealed that premiums as low as 1% and 3% of a family's income caused 15% and 50%, respectively, of those previously enrolled to lose coverage.¹⁹

Similarly, a policy requiring co-payments for prescription drugs often causes low-income individuals to avoid buying prescriptions for essential medications. For instance, Utah's experience of charging Medicaid beneficiaries co-payments of \$2 or \$3 per prescription caused people with incomes below the poverty line (\$20,000 for a family of four in 2006)²⁰ to take smaller doses than prescribed by their doctors to make the medications last longer. When low-income people delay necessary care because it is unaffordable, the delay can exacerbate health conditions, leading to poor health outcomes and even death.²¹

Cost sharing also leads to individuals delaying necessary care, which can exacerbate health conditions that individuals could have prevented or mitigated. For example, when Oregon increased the premiums for enrollees with incomes at and below the poverty line, half of the enrollees – 50,000 individuals – lost coverage. Three-fourths of those individuals became uninsured. These newly uninsured individuals were four to five times more likely to use the emergency room as “their usual source of care.”²² Thus, imposing cost sharing on people who cannot afford it is a classic case of penny wise and pound foolish. The overall health care system absorbs the added cost of treating conditions that have become exacerbated by delay in treatment, and the person who could not afford the treatment suffers unnecessarily in the meantime.²³

b. Cost sharing does not lead low-income people to be more “responsible” health care consumers.

The WG should reject any policy that imposes cost sharing on low-income people and certainly should not seek to justify such an imposition on the grounds that it will create more “responsible” health care consumers. Requiring cost sharing for the purpose of making consumers more responsible wrongly assumes that low-income individuals will forego only care that is relatively less essential, while the studies show that it will reduce essential services as well. Thus, cost sharing would cause low-income individuals to refrain from seeking *necessary* health services, and delaying necessary care will lead to adverse health outcomes.²⁴

RECOMMENDATION: Ensure that low-income people will not be subject to any cost sharing requirements for medically necessary care.

¹⁸ Newhouse, *supra* note 16.

¹⁹ Leighton Ku and Teresa Coughlin, “Sliding-Scale Premium Health Insurance Programs: Four States’ Experiences,” *Inquiry* 36: 471-480 (Winter 1999-2000).

²⁰ Poverty Guidelines, <http://www.aspe.hhs.gov/poverty/06fedreg.htm>.

²¹ Leighton Ku and Victoria Wachino, “The Effect of Increased Cost sharing in Medicaid: A Summary of Research Findings” (2005), <http://www.cbpp.org/5-31-05health2.pdf>.

²² Bill J. Wright et al., “The Impact of Increased Cost sharing in Medicaid Enrollees,” *Health Affairs* 1107 (2005), available at <http://www.ocpp.org/fedbudget/healthaffORcostsharing.pdf>; Ku, <http://www.cbpp.org/5-31-05health2.pdf>.

²³ KU, <http://www.cbpp.org/5-31-05health2.pdf>.

²⁴ Newhouse, *supra* note 19.

2. *Propose a System in Which the Government is the Single-Payer.*

Although the WG proposes that “all Americans [will] have affordable health care,” the WG does not recommend a particular system to implement this goal. We recommend that the WG propose a system in which the government is the single payer. Indeed, the WG found that “most of the public do[es] not view health care as a business that should be driven by the profit motive....”²⁵ In addition, a single-payer system is consistent with Americans’ support for “a national health insurance program, financed by taxpayers, in which all Americans would get their insurance.”²⁶

A single-payer system would save a significant amount of the money currently spent on administration within the health care system, thereby helping to ensure that health care is affordable. Many Americans support a single-payer system because the costs of administration are significantly lower.²⁷ Unlike a multi-payer system of private insurance plans, a single-payer system has lower administrative costs because the system does not have to assess risk, “screen out high-risk clients[,] or charge [consumers] higher fees.”²⁸

Government health insurance programs that operate as single-payer systems for their enrollees have significantly lower administrative costs than those of private health insurance. For instance, Medicare administrative costs are less than 2% of the amount that Medicare spends in benefits.²⁹ In fiscal year 2004, Medicaid administrative expenses were approximately 4.9% of total Medicaid spending, and the administrative expenses for the State Children’s Health Insurance Program (“SCHIP”) were approximately 4.5% of spending.³⁰ In contrast, the administrative costs of private insurance are between three and nine times higher, ranging from 12 -18% of the amount that private insurance companies spend.³¹ Because a single-payer system would save so much on administrative costs, more funds would be available to improve individuals’ health and to make the health care system more affordable for more people.

RECOMMENDATION: Propose a system in which the government is the single-payer.

3. *Propose Financing Strategies That Recognize That Low-Income People Already Contribute Significantly Through Taxes.*

It is possible, as the WG suggests, that securing health care for all Americans will require additional revenues, although eliminating the gross inefficiencies in our current system could greatly

²⁵ *Dialogue*, at 30.

²⁶ *Dialogue*, at 41-42.

²⁷ *Dialogue*, at 30.

²⁸ Paul Krugman, Editorial, *Passing The Buck*, New York Times, Apr. 22, 2005 at A23.

²⁹ Kaiser Family Foundation, Medicare Chartbook 52 (3d. ed. 2005), <http://www.kff.org/medicare/upload/Medicare-Chart-Book-3rd-Edition-Summer-2005-Report.pdf>.

³⁰ Government Accountability Office, Administrative Expenditures and Federal Matching Rates of Selected Support Programs, Report No. GAO-05-839R, 2-3 (2005), <http://www.gao.gov/new.items/d05839r.pdf>.

³¹ Fred Brock, “SENIORITY; Chicken Little Is Ready for Medicare,” *New York Times*, Apr. 11, 2004 at 37. The World Health Organization estimates that administrative expenses of private insurance companies total 15%. Krugman, at A23. In 1999, the administration costs of private insurance was 13.2%. Steffie Woolhandler et al., “Costs of Health Care Administration in the United States and Canada,” *The New England Journal of Medicine* (2003) 349 no. 8 (2003): 768.

diminish the demand for additional revenues. As the Working Group also recognizes, any restructuring of the health care system must continue to pay “special attention” to individuals currently being assisted by government programs, such as low-income individuals assisted by Medicaid. We are concerned that the envisioned financing mechanisms could impose additional financial burdens on low-income individuals. For instance, the WG suggests enrollee contributions, sin taxes or value-added taxes. Like sales taxes, however, these taxes are regressive. Value-added taxes, for example, tax consumption by levying the tax on “transactions instead of people.”³² According to the Congressional Budget Office (CBO), low-income individuals “would pay a larger share of their income in taxes...because the ratio of consumption to annual income is higher for low-income families than for high-income families.”³³

Our support for these types of funding options is conditional on the design of the tax to ensure it does not disproportionately impact low-income individuals. The CBO has described ways to ensure that these taxes are not regressive, such as a bifurcated value-added tax, or credits to low-income households to offset the tax’s impact.³⁴ Therefore, we suggest that the WG recommend that new revenue-raising options be progressive and take into account low-income individuals’ existing tax contributions.

RECOMMENDATION: Propose financial strategies that consider low-income individuals’ existing tax contributions and relative burdens.

4. Protect Low-Income People’s Needs During Full-Scale and Incremental Reform.

Because low-income people are most dependent on government health programs, we urge the WG to state that any changes will protect low-income people’s needs. The phrasing of this pledge will depend on whether the WG recommends full-scale or incremental reform in its final recommendations.

a. Protect low-income people during full-scale reform.

If the WG recommends full-scale reform, such as a single-payer system, we recommend a commitment not to erode in any way the coverage that programs, such as Medicaid and SCHIP now provide. The WG suggests this approach by requiring “special attention to people” whom “private and public programs” serve and by acknowledging it is “critically important” to ensure that “those [who are] unable to afford adequate health coverage” receive needed care. These statements should be expanded into guarantees of real protection.

Because full-scale reform may eliminate the need for programs such as Medicaid and SCHIP, the WG does not necessarily have to pledge to protect a certain program. Instead, a statement of

³² Congressional Budget Office, *The Economic Effects of Comprehensive Tax Reform* 12 (1997), <http://www.cbo.gov/ftpdocs/0xx/doc36/taxrefor.pdf>.

³³ Congressional Budget Office, *Reducing the Deficit: Spending and Revenue Options* 390 (1997), <http://www.cbo.gov/ftpdocs/0xx/doc6/doc06.pdf>.

³⁴ CBO, <http://www.cbo.gov/ftpdocs/0xx/doc36/taxrefor.pdf>, at 15.

protection that focuses on the low-income beneficiaries and medically necessary services that Medicaid and other government health programs cover would appropriately protect low-income people.

b. Protect government programs during incremental reform.

If the WG recommends incremental reform, then we recommend that the WG state that any reform must preserve government programs, such as Medicaid, until any full-scale reform is completely implemented. Because incremental reform may not immediately offer protections equal to or greater than those in existing government programs, preserving the fundamental protections of current government programs is key.

For instance, if a reinsurance system for catastrophic costs were created before establishing a system of affordable preventive health services, it would be necessary to preserve Medicaid's structure to ensure low-income people have health care coverage for non-catastrophic costs. Medicaid's Early and Periodic Screening, Diagnosis, and Treatment ("EPSDT") program for children illustrates Medicaid's significance. EPSDT offers both comprehensive preventive care and medically necessary diagnostic and treatment services for children. Congress has continually strengthened EPSDT because children's access to comprehensive and medically necessary care is critical to child development.³⁵ The number of children with access to EPSDT is significant, with Medicaid covering over 27 million children in 2003, which is more than one in four insured children.³⁶ Thus, specific protection for government programs during incremental reform will be necessary to maintain the foundation that has been built by programs, such as EPSDT for children.

RECOMMENDATION: During full-scale reform, protect the low-income populations that government programs serve. During incremental reform, protect Medicaid and other government programs prior to complete implementation.

B. Working Group Recommendation: Define a "Core" Benefit Package For All Americans.

- 1. Eliminate the Concept of a Core Benefit Package for Low-income People and Replace it with a Guarantee of Access to All Medically Necessary Services at No Cost.*

We are deeply concerned with the concept of a core benefit package as it relates to low-income individuals. As we explained in our comments on the *Values and Principles*, defining a set of "core" services assumes that insurance would cover only some services, and that people would be required to use their disposable incomes to obtain services not covered. Low-income individuals, however, do not have disposable incomes, and therefore simply will have to go without any service not covered in the benefit package. In fact, low-income individuals already pay three times the

³⁵ Sara Rosenbaum, et al., National Security and Child Health Policy: The Origins and Continuing Role of Medicaid and EPSDT (2005), http://www.gwumc.edu/sphhs/healthpolicy/chsrp/downloads/mil_prep042605.pdf.

³⁶ Kaiser Commission on Medicaid and the Uninsured, The Medicaid Program at a Glance (2006), <http://www.kff.org/medicaid/upload/7235.pdf>.

amount of out-of-pocket expenses as a percentage of income than middle and higher-income individuals do.³⁷ Because we believe that costs should not bar low-income people from accessing timely, needed care, we disagree with the concept of making only core services affordable. In fact, the public is in favor of having as many benefits covered as possible.³⁸

Even if the WG concludes that there is insufficient political will to finance all medically necessary services for all income categories, we recommend a policy where all low-income people would have access to all medically necessary health services at no cost. Perhaps (although we are not making this recommendation) higher-income individuals could have a more limited benefit package because they would likely be able to pay for any “optional” services out-of-pocket.

At a minimum, the medically necessary benefit package should cover all low-income people with incomes at or below 200% of poverty, which is \$40,000 for a family of four in 2006.³⁹ The income level could quite rationally be set higher, of course, because even families at incomes above 200% of poverty struggle to pay for health care expenses. For instance, the average annual premium for employment-based health insurance in 2005 was \$11,000, which is over one-fourth of a family’s income at 200% of poverty and still almost one-fifth of a family’s income at 300% of poverty. By means of comparison, federal tax policy currently allows the deduction of any health care expenses that total more than 7% of a family’s income.

RECOMMENDATION: Eliminate the concept of a core benefit package and instead adopt a framework that allows low-income individuals to access all medically necessary services at no cost.

2. *Ensure Comprehensive Coverage for Women’s Health Services.*

If the WG maintains the core benefit concept, it must assure that adequate coverage exists for the needs of low-income women. Americans view women’s health services as essential; indeed, approximately two-thirds of the respondents to the WG’s on-line poll viewed coverage of family planning as “basic.”⁴⁰ For low-income women who cannot afford private insurance, Medicaid provides comprehensive coverage, including “primary and preventive care [services], such as doctor visits, Pap tests and clinical breast exams....” The Federal Government, recognizing the importance of ensuring access to these services, pays for 90% of the costs of Medicaid-provided family planning services and supplies. In addition, the breadth and volume of Medicaid’s coverage is impressive, as the largest payer of publicly funded family planning services in the United States.⁴¹ Further, public health insurance coverage of family planning services has proven to be a cost-effective investment,

³⁷ Leighton Ku and Matt Broaddus, Center of Budget and Policy Priorities, *Out of Pocket Expenses for Medicaid Beneficiaries are Substantial and Growing* (2005), <http://www.cbpp.org/5-31-05health.pdf>.

³⁸ *Dialogue*, at 10.

³⁹ Poverty Guidelines, <http://www.aspe.hhs.gov/poverty/06fedreg.htm>.

⁴⁰ Citizens’ Health Care Working Group, Appendix C: Online Health Care Poll, at 1.

⁴¹ Lourdes A. Rivera, “Medicaid: Supporting Women’s Health, Fighting for Its Life,” (2005), <http://www.americanprogress.org/site/pp.asp?c=biJRJ8OVF&b=466045>.

providing medical, social, and economic benefits.⁴² But the needs of women go beyond family planning, including coverage for regular diagnostic testing (such as Pap tests and mammograms), coverage for labor and delivery, and other essential services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant. Therefore, if the core benefit concept is retained, it must comprehensively cover women's health services.

RECOMMENDATION: Ensure comprehensive coverage for women's health services.

3. Broadly define the standards and evidence that will be used to determine core benefits.

If the WG maintains the concept of a core benefit package in its final recommendations, then it should further clarify how the independent group will make coverage decisions. The WG states that the group might select the services that “meet established standards based on specific levels of evidence, such as clinical trials, effectiveness studies, comprehensive reviews of published analyses, or expert consensus.” We are concerned that while the WG lists examples of evidence the group could use, it does not specify the goal to be achieved. Because the nature of the evidence required will affect the services covered, the WG should clarify that the group will use the broadest evidence possible to prevent undue coverage restrictions.

If, for example, clinical trials are deemed acceptable evidence of efficacy, but not expert consensus, the result could be a narrow definition of core services. By way of example, many pharmaceuticals are not tested on people with disabilities, pregnant women or children because of ethical or legal concerns.⁴³ Thus, a drug routinely be used for these populations – per expert consensus – may technically never have been studied as medically effective for them. We recommend the WG specify that a variety of factors – including standards of practice that professional organizations have developed or that the medical community generally accepts – should be used in determining inclusion in the core package. Standards of practice are recognized as the appropriate method of evaluating medical services, signifying that a consensus exists regarding a particular disease or treatment.⁴⁴ In addition, consideration of a broad array of evidence ensures that health care providers can apply new research before a clinical study has been completed.

RECOMMENDATION: Broadly define the standards and evidence that will be acceptable to determine core benefits.

⁴² The Henry J. Kaiser Family Foundation and The Alan Guttmacher Institute, Medicaid: A Critical Source of Support for Family Planning in the United States 9 (2005), <http://www.guttmacher.org/pubs/medicaid-IB-Gold.pdf>.

⁴³ Sara J. Singer et al., Decreasing Variation in Medical Necessity Decision Making 58 (1999), http://iis-db.stanford.edu/pubs/11389/Decreasing_Variation_in_Medical_Necessity_Decision_Making.pdf.

⁴⁴ See, e.g., Sara Rosenbaum et al, Medical Necessity in Private Health Plans: Implications for Behavioral Health Care DHHS Pub. No. (SMA) 03-3790 (2003), <http://www.mentalhealth.samhsa.gov/media/ken/pdf/SMA03-0790/SMA03-3790.pdf>.

4. *Recommend the Coverage of Language Services to Ensure Meaningful Health Care Access.*

The recommendations fail to address a key facet of health care access: the communication tools that individuals need to secure meaningful health care. Although the *Preamble* lists language as a barrier to care, the WG never offers any solutions to eliminate this barrier. Participants at community meetings cited various cultural barriers to health care, and . comprehensive coverage may be inaccessible to a limited English proficient individual who cannot communicate with his or her doctor.⁴⁵ This is a significant issue, for the number of limited English proficient individuals who speak English less than “very well” totals over 23 million, or 8.6% of the U.S. population.⁴⁶

Providing language services allows limited English proficient persons to accurately communicate with health care providers. “Accurate communication ensures the correct exchange of information, allows patients to provide informed consent for treatment, and avoids breaches of patient-provider confidentiality.”⁴⁷ Other benefits of providing language services include improved health outcomes, lower medical costs, and increased patient satisfaction.⁴⁸

The significance of providing language services is highlighted by some of the egregious errors that could have been avoided if patients had access to language services. For instance, a one hospital admitted a 10-month old child for an adverse medical reaction to a nearly 12.5-fold overdose of a prescription medication. The Spanish-speaking parents of the child administered the dangerously inappropriate amount because they misunderstood the non-Spanish-speaking pharmacist’s demonstration of the proper dosage level. The pharmacy did not have a Spanish-speaking staff, and the pharmacy did not obtain an interpreter to communicate with the Spanish-speaking parents. Additionally, the label on the medication detailing the prescription instructions was written only in English.⁴⁹ Therefore, to ensure that all Americans have true access to covered services, the WG should recommend the coverage of language services.

RECOMMENDATION: Recommend the coverage of language services.

5. *Clarify the Workings of the Private-Public Group.*

If the WG maintains a limitation on covered benefits, then we urge it to clarify key aspects of the group that will identify the services included in the core package and the costs or services included in a catastrophic insurance plan. More specifically, we believe the WG should explain the appointment process of the group, the purpose of the private members, and the decision-making

⁴⁵ *Dialogue*, at 18.

⁴⁶ Bureau of the Census, *Age by Language Spoken at Home by Ability to Speak English: Table B16004*, (2005), <http://factfinder.census.gov>.

⁴⁷ NHeLP, *The Growing Need for Language Services* (2005), <http://www.healthlaw.org/library.cfm?fa=detail&id=72073&appView=folder>.

⁴⁸ Office of Management and Budget, *Report To Congress, Assessment of the Total Benefits and Costs of Implementing Executive Order No. 13166: Improving Access to Services for Persons with Limited English Proficiency* (Mar. 14 2002), <http://www.whitehouse.gov/omb/inforeg/lepfinal3-14.pdf>.

⁴⁹ Agency for Healthcare Research and Quality, “Language Barrier,” (2006), <http://webmm.ahrq.gov/case.aspx?caseID=123>.

process of the group. Knowing the procedural and operational mechanisms of the group is critical to evaluating the group's potential effectiveness.

a. *Explain the appointment process of the group.*

The WG should explain who will appoint the members of the group, and, if a confirmation process will exist, who will confirm the members. Further, the WG should clarify whether members will be professionals in the field, political office holders or appointees, beneficiaries, or all, some or none of the above. These details are essential for us to evaluate if the group's composition really will be independent and non-partisan..

b. *Clarify representation from the private sector.*

All members should be part of the group because of some particular expertise they bring to the process and not because of their affiliation with some segment of the political or economic system. For instance, we would support a person from a private insurance company as a member of the group if that person had expertise in determining the women's health services that a benefit package should include. We strongly disagree, however, with having members from the for-profit private health care market as part of the group if they represent for-profit interests. The WG should not premise membership of the group upon a member's employment in the for-profit sector.

A group with mandatory representation of the for-profit interests of the health care market establishes the private health care market as a stakeholder in the designing of a benefit package and catastrophic health care system. This structure at best would perpetuate the current tension between the desire for quality health care and the desire for maximum profit. Designing the group this way is thus contrary to the WG's findings that "most of the public do[es] not view health care as a business that should be driven by the profit motive...."⁵⁰ Because mandatory representation of for-profit interests may jeopardize the group's independent and non-partisan features, the WG should clarify that the appointment authority would chose members from the private sector based on their expertise rather than based on their representation of for-profit interests.

c. *Explain the decision-making process of the group.*

The WG should explain how the private-public group will make decisions, how congressional input fits into that scheme, and how the WG proposes to minimize the influence of politics in the resulting decision making process. This information is critical in evaluating the group's potential effectiveness.

RECOMMENDATION: If the WG maintains the private-public group in its final recommendations, the WG should clarify the group's appointment process and how it will operate

⁵⁰ *Dialogue*, at 30

C. Working Group Recommendation: Guarantee Financial Protection Against Very High Health Care Costs.

1. Providing Universal Catastrophic Insurance Should Not Be the First Step Undertaken To Improve the Health Care System.

While some form of reinsurance may be desirable, we disagree with the policy of bifurcating the insurance system to provide catastrophic coverage before providing comprehensive health coverage. Rather, we believe reform of the health care system must be comprehensive, or the temptation to stop at catastrophic coverage without essential reforms to the overall system may prove irresistible.

Catastrophic insurance may be one way to reduce premiums on coverage for other health care services, but it fails to address the underlying issues that contribute to the high cost of health care – lack of access to primary and preventive care and other problems with our current system. We are concerned that the WG has apparently failed to consider that many low-income people cannot afford care not covered by a catastrophic policy or even nominal premiums to acquire such a policy. Further, using the private market as the re-insurer likely would lead to increased administrative costs and consequently higher premiums.

2. Establish A System Of Affordable Preventive Health Services Before, Or Simultaneously With, A Catastrophic Insurance System.

Because health is a human right, we should provide not only catastrophic coverage but coverage for all health care needed to attain the highest standard of physical and mental health. For instance, if low-income people delay seeking preventive care because it is unaffordable, they may eventually need higher cost care that could have been avoided. Thus, implementing affordable coverage for primary and preventive care could reduce an individual's use of catastrophic insurance.

Instead of focusing on catastrophic insurance as the first step to reform the health care system, we recommend a single-payer system that covers all medically necessary services for low-income people at no cost. It is the entire health care system that needs fixing, and putting a band-aid on one segment will not address the underlying problems that contribute to poor access and outcomes. If, however, the WG maintains a catastrophic insurance program in its final recommendations, we urge the WG to ensure that coverage of preventive care is provided before, or simultaneously with, coverage for catastrophic costs.

RECOMMENDATION: Start the reform process by implementing a single-payer system that provides low-income individuals with access to all medically necessary health care at no cost. If the WG maintains a catastrophic insurance system, establish coverage for primary and preventive care in addition to covering catastrophic costs.

3. *Specify How A Catastrophic Insurance Plan Will Provide Financial Protection For Low-Income Individuals.*

a. *Clarify how the “high costs” that a catastrophic insurance system would cover would relate to income and other factors.*

In the context of catastrophic coverage, we appreciate the WG’s recognition that health care costs that a middle or high-income family may consider affordable would be catastrophic to a low-income family. The illustration the WG provides, however, does not instill confidence that the WG has fully grasped this concept. The WG suggests that families with incomes at 200% of FPL (\$40,000 for a family of four) could be subject to a deductible of \$12,000. It is totally unrealistic to expect a family to pay 30% of its annual income before a catastrophic policy would cover the remainder. Even for slightly higher income families at 300% of FPL, the deductible would comprise 20% of their income. Thus, the WG should provide more information on it would limit out-of-pocket costs to a reasonable level for everyone, and particularly for low-income families.

Further, the WG states that only income would be factored into the “high costs” for catastrophic insurance. Other factors, however, such as disability or chronic illness, also influence the percentage of income that an individual spends on health care. Thus, we recommend that the WG provide that factors other than income be considered in determining when the “high cost” threshold for catastrophic insurance has been met.

b. *Clarify how an individual mandate to purchase private insurance will be affordable for low-income people.*

Additional information is also needed about the envisioned implementation of the requirement to have catastrophic coverage. It is unclear whether the WG envisions a policy that would mandate all individuals, regardless of income, to purchase private insurance for catastrophic costs. While the WG’s recommendation on affordability acknowledges that low-income individuals would need subsidies, there is no discussion in the rationale of this recommendation. This should be addressed. Because private insurers are likely to deem many low-income people, especially those with disabilities or chronic illnesses, to be “uninsurable,” such people may find that only the private companies with the highest premiums will offer them coverage. As the studies cited above indicate, however, even nominal cost sharing effectively excludes large numbers of poor people from getting necessary health care. Therefore, if the WG ultimately proposes some form of mandatory catastrophic insurance coverage, we recommend subsidizing 100% of the premiums for low-income people.

RECOMMENDATION: Explain how the “high costs” that a catastrophic insurance system would cover are measured in terms of income and disability. Clarify that full subsidies for such insurance will be provided for low-income people

4. *Recommend That The Government, Rather Than The Private Sector, Serve As The Reinsurer.*

a. *A policy in which the private sector is the reinsurer adds new administrative burdens and is unlikely to hold down the costs of primary and preventive care.*

The WG seems to assume that the private sector will provide the reinsurance, since it does not include an illustration of the government in that role. This approach is contrary to the WG's findings that "most of the public do[es] not view health care as a business that should be driven by the profit motive."⁵¹ In addition, bifurcating the insurance system so that an individual would have two policies – one catastrophic and one for other health care costs – would likely result in unnecessarily higher administrative costs, and thus higher premiums or less comprehensive coverage. In addition, a question arises as to how these two policies would interact. The primary insurer would seem to have a disincentive to provide expensive preventive or primary care because the catastrophic insurer would be liable for any resulting adverse consequences from the primary insurer's failure to do so. The catastrophic insurer would then have an incentive to lower its costs by finding ways not to cover the resulting more expensive care. The likely result for a beneficiary is both less appropriate health care and a huge administrative hassle just when she is facing a serious problem with her health.

b. *A policy in which the government is the reinsurer is more efficient.*

The government is much better situated to provide catastrophic coverage. Its programs have much lower administrative costs than exist in the private sector. Also, removing the profit motive will inherently decrease overall costs. Further, only the government would be in a position to regulate the conduct of private primary insurers, so that necessary primary and preventive care is not neglected in order to pass on costs. Finally, the government can spread the legitimate costs of insuring high-risk people over the entire population, rather than over the smaller number of individuals that one private insurance company would serve.⁵²

c. *A policy in which the government reinsures long-term care makes the health care system more efficient.*

We also suggest that any catastrophic insurance cover not only typical catastrophic costs, but also the costs of all long-term care. The percentage of total health care spending attributable to long term care is increasing. Indeed, over the next ten years spending on home health care alone probably will double.⁵³ In 2005, the average cost of nursing home care was over \$74,000 per year, which equates to \$203 each and every day.⁵⁴ Someone has to pay for this care, and removing these costs from traditional health insurance – and ensuring that the savings are passed on to enrollees and their health care purchasers – would reduce the premiums that individuals will be required to pay for their primary care. This increased efficiency would allow more funds to be available to make health care affordable for low-income people.

⁵¹ *Dialogue*, at 30.

⁵² Katherine Swartz, "Government as Reinsurer for Very-High-Cost Persons in Nongroup Health Insurance Markets," *Health Affairs* W380 (2002).

⁵³ *The Health Report to the American People*, at 4.

⁵⁴ *BusinessWeek*, *Nursing Home Costs up 5% in 2005*,

http://www.businessweek.com/the_thread/wellspent/archives/2005/09/nursing_home_co.html (Sept. 27, 2005).

RECOMMENDATION: If the WG maintains a catastrophic insurance system, recommend the government as the reinsurer for both catastrophic costs and long-term care.

D. Working Group Recommendation: Support Integrated Community Health Networks.

1. Support Initiatives That Serve Vulnerable People.

We support the WG's recommendation for national initiatives to develop and expand community health networks that serve vulnerable populations. These initiatives signify a willingness to invest in public health programs that help low-income people achieve access to quality, affordable health care. We support national coordination of these efforts, and having a national group that would advise the federal government on safety net issues.

2. Identify Language Access as a Tool Needed for Meaningful Health Care Access.

The WG suggests integrated community health networks as a way to solve the multi-faceted health care access problems that many individuals face. Because language barriers are a critical impediment to health care access, we urge that the WG include improving language services as a specific objective.

Comprehensive coverage will not be available to a limited English proficient individual who cannot communicate with his or her health care provider. The number of limited English proficient individuals who speak English less than "very well" total over 23 million, or 8.6% of the U.S. population.⁵⁵ Expanding language access services provides myriad benefits, such as improved health outcomes, lower medical costs, and increased patient satisfaction.⁵⁶ Thus, to ensure that community health networks deliver quality care that is culturally competent, the WG should the provision of linguistic services as part of the national health care initiatives.

RECOMMENDATION: Include the provision of language services as a goal for the national health care initiatives.

3. Insure sufficient funding for the expansion of health centers.

We support the expansion of the FQHC concept, but care must be taken so that the expansion does not occur at the expense of existing health centers. FQHCs serve a critical role for vulnerable populations. It would be counterproductive to expand FQHCs if doing so led to a funding shortfall for existing centers, thus further stressing their already strained resources. We recommend that the WG pair its proposal to expand health centers with a commitment to provide sufficient resources for the task.

⁵⁵ Bureau of the Census, Age by Language Spoken at Home by Ability to Speak English: Table B16004, (2005), <http://factfinder.census.gov>.

⁵⁶ Office of Management and Budget, *Report To Congress, Assessment of the Total Benefits and Costs of Implementing Executive Order No. 13166: Improving Access to Services for Persons with Limited English Proficiency* (Mar. 14 2002), <http://www.whitehouse.gov/omb/inforeg/lepfinal3-14.pdf>.

Any expansion must include new resources to ensure that all health centers have the capacity to deliver high quality health care.

RECOMMENDATION: Pair the proposal to expand health centers with a commitment to provide sufficient resources for the task.

4. *Preserve patients' opportunities to comprise a majority of the seats on an organization's governing boards.*

The WG proposes to modify the FQHC concept to encourage federal support for additional community-based providers, but it is unclear exactly what modifications are contemplated. For instance, the WG proposes to relax FQHC eligibility requirements for federal funds. We urge the WG to keep the existing requirement that patients comprise a majority of an FQHC's governing board as a condition of receiving federal funds. The governing boards decide a variety of health care delivery matters, such as the services a center may provide or the manner in which it operates, and these are decisions that the affected community should control. Further, because FQHC's serve a disproportionate number of low-income and uninsured people, having patients be a majority of the board gives a voice to those who often go unheard and ensures that new centers will be responsive to those they serve.

RECOMMENDATION: Preserve the requirement that patients occupy a majority of the seats on an organization's governing board as a condition for the organization to receive federal funds.

E. 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.

1. *Broadly Define The Scope Of "End-Of-Life Services."*

The WG does not define the scope of "end-of-life services" nor what specific services need restructuring. The language of the recommendation appears to focus on care in the "last days" of life, but also utilizes the terms "palliative care," "hospice care," and "care of the dying," which can refer to varying types of services and lengths of treatment. For instance, palliative care is not limited to relief of suffering in the terminally ill; it can refer to care with the same aim across a broad spectrum of illnesses.⁵⁷ Likewise, hospice care generally is understood to focus on the last 6 months of life, but

⁵⁷ Institute for Ethics at the American Medical Association, Education for Physicians on End-of-life Care (EPEC): Elements and Models of End-of-life Care (1999), pg. P3-1, http://www.ama-assn.org/ethic/epec/download/plenary_3.pdf.

can also be synonymous with palliative care and thus not time-limited.⁵⁸ The WG should clarify where “end-of-life” care falls on the spectrum between “last-year-of-life” and general “long-term” care.

NHeLP is concerned that a narrow definition – limited to the last year of life - does not adequately address the needs of seriously ill patients and their families, particularly low income individuals. The average stay of an individual in a nursing home is about 2.4 years.⁵⁹ A definition of end-of-life care limited to the final year ignores the needs of these individuals beyond that period of time. We recommend that end-of-life care be defined to include long term care. However, if the WG limits its focus to the last year of life, it should include all relevant services. As with the core benefit package, any definition that excludes certain services effectively precludes low-income individuals from accessing them. Thus, the definition of end-of-life services should be expansive.

The definition is particularly important because end-of-life services are extraordinarily expensive. As the WG cites, last-year-of-life expenses constitute 22 percent of all medical expenditures. It is also estimated that 28 percent of Medicare spending is concentrated on the 5 percent of enrollees in their last year of life.⁶⁰ These high costs can constitute a huge financial drain on patients and their families at all socioeconomic levels, but the impact is magnified for low-income families ineligible for Medicaid, who often lack savings reserves. Low-income families may have no choice but to care for the seriously ill patient at home. This caregiving may force them to leave paid work and forego income, putting the rest of the family in financial jeopardy. Without coverage of end-of-life services, low income families are faced with the difficult choice between obtaining the necessities of life and caring for a loved one at their neediest time.

End-of-life services not funded or covered will drastically reduce low-income patients’ access to these services. Thus, we urge the WG to expansively define end-of-life services.

RECOMMENDATION: The WG should define the length and scope of “end-of-life care” expansively, taking into account the increased burden of such services on low-income patients.

2. Propose A System In Which The Government Covers End-Of-Life Care.

We also recommend that the federal government be responsible for financing end-of-life services. Federal sources of funding currently fail to adequately cover the prohibitive costs of end-of-life care for many individuals. Medicaid is the leading source of funds for long term care, accounting for 42 percent of total spending on such care in 2004.⁶¹ However, Medicaid does not cover all low-income and elderly populations that may require end-of-life care. And Medicare does not generally

⁵⁸ *Id.* at P3-10.

⁵⁹ Centers for Disease Control and Prevention, Nursing Home Care, <http://www.cdc.gov/nchs/fastats/nursing.htm>.

⁶⁰ Lubitz, J.D. and Riley, G.R., “Trends in Medicare Payments in the Last Year of Life.” *The New England Journal of Medicine* (1993) 328: 1092-1096.

⁶¹ Kaiser Family Foundation, Fact Sheet: Medicaid and Long-Term Care Services (2006), <http://www.kff.org/medicaid/2186.cfm>.

cover long-term care at all,⁶² even though the beneficiary population is most susceptible to life-threatening illnesses. Given this situation, patients, and also their families, are often impoverished if they require long-term care. As discussed earlier in these comments, only the federal government is in a realistic position to fund such care, and doing so will lessen the pressure on primary care premiums if the private sector continues to insure that coverage.

RECOMMENDATION: The federal government should fully fund end-of-life services.

3. *Support Initiatives That Help End-Of-Life Patients Understand Their Health Care Options, Make Their Choices Known, And Have Those Choices Honored.*

a. Support training and resources for adopting culturally sensitive end-of-life care models.

NHeLP fully supports and affirms the WG's recommendation that culturally sensitive care models are necessary to improving end-of-life care. Studies have shown that aspects of an individual's background, whether race, ethnicity, culture, or religion, may profoundly impact preferences for end-of-life care. For instance, studies have demonstrated race-related differences in attitudes towards life-prolonging interventions.⁶³ Given that clear and open communication may be difficult for any patient facing the end-of-life, efforts to hear and understand these subtexts are particularly critical for improving their care.

Health care professionals vary widely in their cultural competency. We support the provision of training and resources to help health professionals facilitate clear communication between providers, patients and their families and provide care that is sensitive to the cultural and other needs of each unique patient.

b. Define language services as necessary to “clear communication” between providers and patients and the provision of “culturally sensitive” end-of-life care.

While an understanding of the patient's background and culture is helpful, it is not the only consideration in end-of-life decision-making. Ultimately, the individual's own values and wishes must be sought and heard. We assume that the WG considers language access tools a necessary part of providing meaningful end-of-life care. For the over 23 million limited English proficient individuals in this country, language can be a barrier to achieving dignified end-of-life care. Providing language services allows limited English proficient persons to effectively convey their preferences and beliefs to health care providers. Although family members may be present and willing to facilitate the discussion, their participation often creates problems. One study noted that errors by “ad hoc” interpreters – including family members and friends – are significantly more likely to be errors of

⁶² Centers for Medicare & Medicaid Services (CMS), “Paying for Long-Term Care,” (2006), <http://www.medicare.gov/LongTermCare/Static/Medicare.asp>; see also CMS, “Medicare Coverage of Skilled Nursing Facility Care,” (2004), <http://www.medicare.gov/Publications/Pubs/pdf/10153.pdf>.

⁶³ EPEC: Elements and Models of End-of-life Care (1999), pg. P3-4, http://www.ama-assn.org/ethic/epec/download/plenary_3.pdf.

potential clinical consequence than those committed by hospital interpreters.⁶⁴ To ensure that all patients can clearly communicate their end-of-life preferences, we recommend an explicit acknowledgement from the WG that coverage of language services is essential to improving end-of-life care for all patient populations.

RECOMMENDATION: Support initiatives that provide language services and give health care providers the resources to provide culturally sensitive care in the end-of-life setting.

4. *The WG Should Broadly Define “Evidence-Based Science.”*

NHeLP supports basing the coverage of health services on accepted standards of evidence. As discussed earlier, however, we suggest the WG define “evidence-based science” broadly to include accepted off label uses and to ensure that the term is not limited to evidence such as clinical trial results, which may not consider all relevant patient populations.

RECOMMENDATION: Broadly define “evidence-based science” to include evidence which considers diverse patient populations.

F. Working Group Recommendation: Promote efforts to improve quality of care and efficiency.

1. New Health Information Technologies And Electronic Medical Record Systems Should Collect Patient Data On Race, Ethnicity, And Primary Language.

NHeLP agrees that a greater investment in health information technology and integrated electronic health records systems could advance quality improvement and health care outcomes. In addition to the benefits enumerated by the WG - reductions in medical mistakes, greater administrative efficiency, better-informed consumers - we suggest that health care information systems can be a powerful tool for addressing health disparities.

As new programs and technologies are implemented, we recommend mandating the collection of race, ethnicity and primary language information in a manner that is interchangeable among systems. The collection of reliable, consistent, and comprehensive data is an essential first step towards eliminating health disparities. The data can be used to identify differences in quality across geographic, cultural, language, and ethnic communities and then to develop effective quality-improvement strategies.⁶⁵ For example, if a system to reward high-quality providers is implemented, this data could be used to ensure that the same quality of care is being provided to all communities. We also appreciate the WG’s recommendation that these new information systems be implemented in

⁶⁴ Glenn Flores, *et al.*, *Errors in Medical Interpretation and Their Potential Clinical Consequences in Pediatric Encounters*, *Pediatrics*, Vol. 111, No. 1 (January 2003).

⁶⁵ See, e.g., Ruth T. Perot and Mara Youdelman, *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices*, The Commonwealth Fund, Report 492 (September 2001), http://www.cmwf.org/publications/publications_show.htm?doc_id=221295.

clinics and hospitals caring for underserved populations. The required collection of key patient data at these sites in particular will help maximize the impact on quality of care.

We support the WG's belief that medical information should be shared "safely." Although public reporting of data and analysis is essential to improving quality, we emphasize the importance of maintaining the privacy and confidentiality of medical data. Failing to properly safeguard such information can subject certain individuals to discriminatory treatment, and will certainly decrease their willingness to cooperate in its collection. For instance, many health care consumers are concerned that employer access to their health information could result in the inappropriate use of such information in hiring, firing or promotion decisions.⁶⁶

RECOMMENDATION: As new health information systems are implemented, prioritize the collection of racial, ethnic, and language data and then insure true confidentiality of the information collected.

⁶⁶ Janlori Goldman and Zoe Hudson, Health Privacy Project, "Exposed: A Health Privacy Primer for Consumers," (1999), http://www.healthprivacy.org/usr_doc/34775.pdf.