Citizens' Health Care Working Group Meeting
United Food and Commercial Workers International Union
1775 K Street, NW, 11th Floor
Washington, DC
Wednesday, June 21, 2006 and Thursday, June 22, 2006

Meeting Summary

Working Group Members Present:
Randy Johnson, Chair
Dotty Bazos
Frank Baumeister
Montye Conlan
Richard Frank
Joseph Hansen
Therese Hughes
Catherine McLaughlin
Pat Maryland
Aaron Shirley
Deb Stehr
Don Young (Representing the Secretary, HHS, Michael Leavitt)

Working Group Staff Present:
George Grob, Executive Director
Suzanne Amoonarquah
Jill Bernstein
Craig Caplan
Jessica Federer
Elyse Goldenberg
Margretta Kennedy
Andy Rock
Caroline Taplin

Other Attendees:
Mary Giffin, GAO
Hala Harik Hayes, America*Speaks*
Susanna Knouse, PFI
Mark Marich, PFI
Jonathan Ortmans, PFI
Mary Ella Payne, Ascension Health
Carol Regan, UFCW

Randy Johnson, the Chair, began the meeting at 8:30 a.m., Wednesday, June 21, 2006. Jonathan Ortmans, PFI, facilitated the meeting. PFI also provided wireless keypads to enable the Working Group to conduct anonymous ballots on key decisions.

Most of the meeting was devoted to a discussion of the Interim Recommendations.

The moderator indicated that the day's discussions were not about changing the Interim Recommendations but rather about refining and clarifying them by providing rationales and discussion.

Catherine McLaughlin asked whether the Working Group was going to agree to the words for the rationales and then post them on the Working Group web site. She indicated that her belief that the decision at the last meeting had been that because the Working Group changed the recommendations the accompanying rationales also needed to be changed and staff had been asked to adjust the accompanying additional language to comport with the recommendations. She indicated that that the recommendations without rationales could be difficult for the public to understand.

Randy Johnson suggested going through the proposed language that fleshed out the recommendations and then separately address the question about whether to add the language to what was available on the web. He suggested coming back to the question about posting on the web and decide it once the Working Group was through refining the rationale/discussion language that would accompany each recommendation.

The moderator asked whether there were other issues that needed to be added. Additional issues suggested by the Members were:

- Deb Stehr – Discuss the impact of the proposals on Medicaid.
- Catherine McLaughlin – Insert the role of the private sector into recommendation 5 and provide some discussion. Add language to rationale for recommendation 4 that discusses broader issues consistent with what was heard from the public.
- Dotty Bazos – "Connect the dots" in the document in order to present a cohesive (not "fragmented") plan; based on the public's response thus far, it appears that the public is unsure how it all fits together. Throughout the document there is not enough bridging language to connect the proposals. A roadmap is needed indicating where the total package of proposals are going. A graphic is needed to illustrate connections between recommendations. (Other Members also agreed with the need for a graphic.) The quality material needs to be linked to the other recommendations. There needs to be discussion of the core benefit package.
- Montye – Add more emphasis on the mainstream middle class; the needs that everyone have should be addressed, not just those of vulnerable populations.
- Richard Frank – The Working Group did not vote on the dates by which Recommendations will be achieved that are included in the version of the Interim Recommendations that have been posted on the Web. It is important that no statements appear that the Working Group has not voted on. The Working Group needs to revisit the dates and vote on them if they are going to remain in the Recommendations.
- Montye – Reexamine the 2012 date; this seems too far in the future.

Discussion of Published Interim Recommendations

This section provides:

*1. Draft rationale/discussion text for Working Group consideration at the meeting -- shown in ITALICIZED **BLACK** font.*
2. Working Group and Staff comments at the meeting -- in **RED** font.
3. Text of the Interim Recommendations, as published June 2, 2006 -- in BLUE font**.**
4. Issues and suggestions prepared by Staff -- in GREY boxes.

The order below follows discussion at the meeting, NOT published order of the recommendations. The following first paragraph was proposed to precede all the recommendations:

These recommendations, which we believe reflect the principles and values we derived from our dialogue with the American people, call for a fundamental change in health care in this nation. We recognize that this transformation will be challenging, and will take time, and a great deal of work. The following recommendations constitute a three-part strategy for moving ahead. The first step is a commitment to a longer-term vision; the second step consists of interim solutions that within current budget constraints can address immediate problems facing those of us at greatest risk now; the third step is designed to promote the development of the tools and systems we need to achieve the broad goal of health care that works for all Americans.

Dotty Bazos – This first section would be the place to put the public's view that the system is in crisis; we should put that right up front that the system is in crisis; there was a lot of passion at the meetings that needs to be reflected here. This introductory paragraph needs to be changed to express a longer term view and a need for fundamental change.

Montye – That might necessitate even more specifics in the recommendations, and that may be difficult to do.

Frank Baumeister – There may be significant changes in the Final Recommendations that go to the Congress and the President.

Richard Frank – Some of the things in this paragraph need to be changed. It needs to say that achieving changes through Step Two (high cost protection and community health development) should not be limited to people at extreme risk. The proposals should be expressed as a modest step in the direction of our goal, which if enacted and if it is meaningful would be worthwhile even if nothing else is done.

Dotty Bazos – The second step (developing community health systems) affects all Americans; that needs to be clearer and then transition into the vision. The paragraph needs to explain the relationships among the various recommendations, how they tie together, and what the interim steps are.

Therese Hughes – It needs to clearly state that the overarching goal is health care that works for all Americans.

Catherine McLaughlin and Montye Conlan agreed to the need for such language.

Frank Baumeister – The language is too vague and should be more specific. Everybody is at risk of bankruptcy and impoverishment, not just "those at greatest risk." The latter phrase implies welfare and the poor, not health care for all.

Catherine McLaughlin – The wording needs to be changed; "greatest risk" implies poor people and that's not what we mean. We are all at risk. These buzz words send certain signals so we need it to be painfully obvious that it is clear that this applies to all Americans.

Montye – The average person needs a little bit more to understand our thinking.

Aaron Shirley – Could the 4-5 Members, not staff, who feel that the words need to be changed get together and come up with language? If I were the Chair, I'd appoint Richard Frank, Montye, Catherine McLaughlin, Dotty Bazos, and Frank Baumeister to revise the language.

Randy Johnson – "Within current budget constraints" is unclear; it means "without more budgetary allotment" to me and we may need to clarify that.

Don Young – Each recommendation will be looked at on its own and needs to stand alone; if there are conflicts, these need to be worked out. What you want in each recommendation needs to be explicit and clear.

Frank Baumeister – Staff can do this.

Richard Frank –It can be revised outside of this meting, redrafting and circulating versions among staff and Members can be done over the next several days.

- **IMMEDIATE PROTECTION FOR THE MOST VULNERABLE: Action should be taken now to better protect Americans from the high costs of health care and to improve and expand access to health care services.**

Recommendation 3:
Guarantee financial protection against very high health care costs.

No one in America should be impoverished by health care 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.

Rationale

Affordability of care was a primary concern among participants in community meetings. At meetings throughout the country, individuals discussed how costs had prevented them or others from getting needed care. At many of the community meetings, participants were asked what they believed was the most important reason to have health insurance. Although the results varied by meeting site, about 60 percent of participants in community meetings and in the Working Group Internet poll said that the most important reason to have health insurance was "to protect against high costs," compared with about 34 percent who said it was to pay for everyday medical expenses. At most meetings and in many of the comments submitted to the Working Group, people described disastrous results of high medical costs, including families losing their businesses, their homes, and their life savings due to high health care expenses. National polls have also found that the cost of health care dominated Americans' concerns about health care overall.

Discussion

It is important to clarify and distinguish the objectives of this recommendation. Guaranteeing that no one in America should be impoverished by health care costs, if taken literally, would mean providing protection for all families against out-of-pocket health care payments that drop their income below the subsistence level, leaving them unable to pay for other basic necessities. This is not the same as providing protection against high health care costs. In and of themselves, high medical care costs may not bankrupt a family, either because they have high income or because they have health insurance coverage that pays for much of the costs. At the same time, what on the surface appear to be health care services with relatively low costs may in fact bankrupt a family with low income and little or no health insurance.

[Should this be included: There are many variations of a Federal program that would ensure that no family will be bankrupt by ill health, several of which have been proposed in the past. All have struggled with achieving the goal of protection and maintaining administrative simplicity and program affordability. Providing families coverage for out-of-pocket costs of more than, say, 40 percent of their income may be administratively simple and affordable, but would not protect those with low incomes from falling below subsistence. On the other hand, placing the cap at 5 percent of family income would no longer be catastrophic coverage for many.]

We propose a policy that blends these concepts of high cost by providing protection against out-of-pocket costs that exceed some percentage of income, say 20 percent of taxable income above the Federal poverty level, or a fixed dollar amount of individual liability, say $30,000 whichever is lower. All Americans would be required to purchase catastrophic health insurance. We propose that individuals must demonstrate that they are covered by an appropriate policy when filing annual income taxes. If individuals cannot afford private catastrophic coverage, subsidies would be made available via refundable tax credits. Standards for a set of appropriate catastrophic polices would be set by the Secretary of HHS.

[Should this be included: In addition to providing some level of financial security to everyone, this recommendation could help stabilize health insurance markets. Expanding this coverage to all might allow individual and small group insurers to increase access to insurance in the marketplace, including for people now considered "uninsurable."]

Catherine McLaughlin – Add language about regulating qualified plans; there need to be regulations just like for Medigap and Part D plans so that consumers aren't short changed. There needs to be some policies for quality control. As it's currently written, the proposal would not be another Federal plan. We haven't discussed that. If it is a Federal plan, some will object. People don't complain too much about Medigap plans because there are standards.

Richard Frank – The banner "Immediate Protection for the Most Vulnerable" and related text should be removed. It was not voted on. The catastrophic proposal is intended to provide protection for everybody. It potentially creates benefits for the small-group market and others. It is supposed to create opportunities to fill in where the market doesn't do it by itself. The model I'm using was the catastrophic insurance proposal from the '93 Congress; we are allowing the private market to operate and have the government as a back-up.

Catherine McLaughlin – There is a difference between insuring against high costs and catastrophic costs; if we focus on catastrophic, there are different ways to address this. It is complicated and the threshold for what would constitute "catastrophic" would vary in amount at different income levels. This proposal was intended to address distinctions between the poor, the majority middle class, and wealthy. We proposed a blend of percent and aggregate dollar amounts to address differences in financial risk. For our purposes, we used the Federal Poverty Level as a floor. The proposal wasn't meant to be prescriptive but rather illustrative. The 20 percent figure included in the proposal was a starting point for discussion.

Randy Johnson – How would this work in conjunction with other coverage that people have under employer-sponsored insurance and health savings accounts (HSAs)? How are we going to pay for this? How does it coordinate with "stop loss" policies?

Richard Frank – Let's take people that have an HSA, for instance, a Motorola plan.
Randy Johnson – Why would Motorola provide employer-based coverage if you are providing it?

Richard Frank – Everybody would be required to have insurance: it would be an individual mandate for catastrophic coverage. For low income individuals, there would be subsidies for purchasing it. Motorola would have the very same incentives to provide it as it does now because there would be no subsidies for its employees. The individual would have to show in his tax return that he has insurance It could fit in with any larger financing scheme like tax credits, other subsidies, or state-provided plans. Any of those financing schemes could work with this. It wouldn't preempt private market plans or systems.

Randy Johnson – If we're going to have this kind of catastrophic coverage; then why would we need a core set of benefits also?

Richard Frank – That's a different story. If you don't believe that catastrophic is enough, then you need to have other plans. If people need coverage below the catastrophic limit, you'd have other plans. The catastrophic plan is a fairly easy one to do.

Catherine McLaughlin – The catastrophic provision would prevent impoverishment; however it doesn't address preventive services; so the question is whether people want this also to be provided.. The consumer panel we are proposing might say that catastrophic coverage is sufficient but they may want broader coverage. This proposal only addresses impoverishment resulting from very high health care costs.

Don Young – What is meant by "out of pocket" in the recommendation may need to be clarified.

Randy Johnson – Who's going to design this and run it? How would it be underwritten?

Richard Frank – An associate who works at Aetna claims that these plans already exist.

Randy Johnson – I'm unclear about the link between the subsidy and personal income.

Richard Frank – Medicare Part D is a model; it is similar to what we are proposing. People have responded regarding proposals for catastrophic coverage more than many might have predicted. Many from the ideological left to the right have had ideas about how to do this. People from many backgrounds, including industry, have indicated that this is do-able.

Catherine McLaughlin – Our mission is to reflect what we've heard from the public and we heard that "no one should be impoverished" and that "everyone should contribute" and "people should contribute based on their ability to pay." I don't think we can go much further than what we've heard.

Richard Frank – We also can't staff out much more detail that we have already proposed.

Montye – How do we guarantee that insurance companies will offer protection? If they don't sell the coverage, what good does a subsidy do?

Catherine McLaughlin – If it is a mandate, there will be pooling of risk and insurance companies will be willing to provide insurance. Right now, only the very high risk persons are purchasing insurance so the rates are high or insurance is not being made available by the private market.

Richard Frank – If there are some places (regions, cities, etc.) where things fall apart, then you have some fall back plans -- such as the state stepping in and providing the coverage system.

Montye – Isn't it possible that companies may simply not offer certain types of coverage, say for particular drugs, under this plan? To prevent this, the "fall back" plan would have to be a guarantee. Insurance companies have a way of getting out of liability risk. The devil's in the details.

Aaron Shirley – Drug companies are not mandated to cover all drugs.

Randy Johnson – Private carriers may not want to pick this up and then government would have to step in.

Richard Frank – Private insurance companies will be very interested in this. Congress will have to work something out; we can work out all the details. Either you agree that we set the bar at the lowest level of shared social responsibility or not.

Dotty Bazos – Is the plan the same cost for everyone? If a personal mandate, then most of us have this already. What if everyone paid for this through taxes and all the dollars were collected through taxes. Then, would our premiums go down some proportionate amount? The system for collecting the dollars/premiums seems cumbersome. If done through taxes, does that influence companies' responses?

Catherine McLaughlin – Most of us already have this now -- through our employers

Richard Frank – If you collect/run the program through the government, you raise the concern of those who don't want government to be central.

Catherine McLaughlin – The uninsured and underinsured fall into two piles. The overwhelming numbers of Americans are going to be able to afford the price of premiums; it's around $1,000 a year. It's not that high a cost.

Randy Johnson – Part of the reasons those programs aren't selling very well is that they keep some people with diseases out of the system.

Richard Frank – You will have to regulate it to prevent exclusions. The proposal is agnostic regarding the way in which the funds are collected – it could be government or it could be private.

Dotty Bazos – How does the proposal address the concerns of many Americans who are having difficulty identifying and dealing with insurance companies?

Richard Frank – There are a lot of ways to do this. Can't we get an idea on the table that solves some problem that is a workable solution that the Congress could decide to wrestle with that could be done in a reasonable period of time? The limited proposal presented addresses all these things. There are two ways it could be done: the government sets up the plan; alternatively it would be through an individual mandate, through the rulemaking process, and a mechanism like Part D could be set up.

Randy Johnson – I'm still thinking about the introductory phrase, "within current budget constraints" and wondering how this is possible consistent with that language.

Richard Frank – I agree it's an issue and I didn't agree with the language about current budget constraints.

Catherine McLaughlin – Catastrophic coverage plans have failed because of the absence of an individual mandate. The young and uninsured are also at risk and should be required to participate. The individual mandate is the key issue.

Dotty Bazos – How would small employers respond to this proposal?

Catherine McLaughlin – They will want it too.

Richard Frank – There's evidence that this sort of approach would work.

Pat Maryland – I'd like to see additional rationale added explaining this.

Therese Hughes – I think it is good we want to have a catastrophic coverage plan. But it's going to be a very costly plan. Kidney failure, obesity, diabetes, etc., are high cost. It is unclear how affordable this proposal is at the macro level

Montye – What happens in 2020 when people have been paying for this and societal health circumstances change and it then gets too expensive when people have had the expectation over years that they will be covered – say an epidemic comes along and changes the economic equation? I want some safety net; the private sector doesn't assure that the safety net is there.

Randy Johnson – Please explain the role and function of the $30,000 limit.

George Grob – We need also to look at the impact. Under the proposed formula, for a family of four, the $30,000 limit would not come into play until the family income was at least $170,000. For a four person family with $50,000 annual income, the limit would be $6,000. These examples indicate the relation between income and maximum financial impact.

Catherine McLaughlin – For an individual, the Federal poverty level (FPL) is about $10,000. So, say you earn $20,000, and then the maximum cost in a year to you would be $2,000 under this plan.

George Grob – Do Richard Frank and Catherine McLaughlin want to do another draft?

Richard Frank – With Montye also.

George Grob – Therese Hughes as well.

Dotty Bazos – Do we want to include in the recommendations citations to other work that has preceded us?

Jonathan Ortmans – Do any have objections to having references to other studies? (None heard)

Don Young – You probably don't need it; unless as an appendix; these are your recommendations. It is a really big sea change to have the Secretary set the standards; you could have the National Association of Insurance Commissioners (NAIC) set the standards; but then you lose uniformity. You could have the Secretary set broad standards and leave the rest to NAIC. The issue is regulations which, in addition to statutory changes, would be significant. You have to decide how much specificity you want to provide; the tradeoff is that less means that others, who apply the policy have more discretion. Private insurance has been state-regulated and my bias is that it should stay so.

George Grob – A relevant point is the perceived "mistake" in deeming much standard-setting authority to the Joint Commission on the Accreditation of Health Care Organizations.

Jonathan Ortmans – A summary of actions steps based on the foregoing would include adding language to :

- Clarify what constitutes out of pocket expenses
- Discuss impact on small business, young adults and early retirees
- Make clear that all must participate
- Discuss minimizing impact of potential large-scale system changes
    - Guarantee that people would not be turned down for coverage
    - Will this program run out of funds?

Catherine McLaughlin – I think we should consider, as one of the issues: should government be a fall back?.

Frank Baumeister – I agree that we should consider later whether we seek a public financing mechanism.

Catherine McLaughlin – Once you get to the limits, the potential spending is unlimited. My response has always been that most people don't want health care just because it's free, they want it because they are sick. The expensive items are not ones that people would actively seek; the routine type of care is relatively inexpensive.

Don Young – A rough rule of thumb is that people without insurance consume about half as many dollars of service as those with insurance. Those with other coverage would be affected and included in the financial analysis.

Randy Johnson – So, under this catastrophic coverage proposal, nothing is paid until the person reaches the lower of $30,000 or 20 percent of income.

Catherine McLaughlin – This catastrophic mandate will cause the insurance plan costs for overall health insurance premiums to go down by 25%.

Randy Johnson – Employers may say “we’re out of the business” for this catastrophic coverage. Employees will be better off under this program than under their private plan.

Catherine McLaughlin – If the employers conclude that because there is a mandate and a market for catastrophic insurance and stop providing it, the company will have to compensate the individual in some other fashion.

Randy Johnson – In the Motorola example, there would be some significant impact. Motorola might get out of the business because it determines that their older employees would cost more.

Richard Frank – However, of all the options, this is the one that distorts the market the least.

- **CORE BENEFITS: Americans will have access to a set of affordable and appropriate core health care services by the year 2012.**

Richard Frank – I'm troubled by the date; we didn't vote on it. There can't be things in the recommendations that we didn't vote on. None of the three arrow headings that appear in the published Interim Recommendations was voted on by the Working Group.

Recommendation 1:
It should be public policy that all Americans have affordable health care.

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

Across every venue we explored, we heard a common message: *Americans should have a health care 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.*

Rationale

In community meetings throughout the nation, an overwhelming majority of participants told the Working Group that "it should be public policy that all Americans have affordable health care." In the discussions underlying values and perceptions that began each community meeting, 94 percent of all participants agreed with this sentiment. Similarly, 92 percent of respondents to the Working Group's Internet poll strongly agreed (80 percent) or agreed (12 percent) with this statement. People at many of the community meetings expressed the desire for "cradle to grave" access to health care.

A clear majority of participants at every community meeting preferred that all Americans receive health care coverage for a defined level of services. Between 68 percent and 98 percent at all community meetings said that we should provide a defined level of services for everyone. In the Working Group's Internet poll, 85 percent of participants also opted for a defined level of services for everyone. These findings are also consistent with the results of other national polls asking similar questions. In surveys conducted by other organizations, a clear majority have expressed the opinion that all Americans should have health insurance. For example, a national poll conducted in September 2005 found that 75 percent of U.S. adults somewhat favored (23 percent) or strongly favored (52 percent) universal health insurance.

Discussion

What kind of health care system do Americans want? People told us they want a system which guarantees health care for everyone, but not, at least not with as much consensus, national health insurance. This distinction between health care and health insurance is critically important. The notion of health care we heard about focused on access and security. People are seeking a system in which everyone is "enrolled" in a plan that covers most health care costs and, unlike the current system, cannot be cancelled, lost due to change of employment, priced at levels that are unaffordable, or not cover some people because of previous or ongoing health problems. The health care system envisioned by the people we heard from would provide

comprehensive coverage for preventive care, treatment of illness and injury, and palliative care, with a level of cost-sharing that does not keep people from getting that care. It would be a system that respects the value that Americans place on choice of providers, and one that enables consumers to make good decisions about their health care.

We heard a wide variety of views about how we as a nation could accomplish the goal of health care for all. Many of the people we heard from believe that either Medicare or the Federal Employees Health Benefits Program could serve as a basic model for a national system for everyone; some also singled out the Veterans Health Administration (VA) system as a possible model. Others suggested that some of the large integrated managed health care systems (Therese Hughes – I recommend that specific examples, like "Kaiser" and "IFC" be specifically mentioned)(No consensus reached on this suggestion.) *that now provide care to large numbers of people in some parts of the United States could provide good models. People pointed to these programs not only as examples of how to provide coverage, but also as systems that can better control costs and provide the infrastructure and resources needed to improve the quality and efficiency of health care delivery. Some of these systems are administered by or through private sector health plans; others are run directly by government* (Dotty Bazos – Make this the second sentence of the paragraph; then add more detail).

Catherine McLaughlin – Why not be honest about the fact that some citizens we heard from stated that they wanted a single payer? I'd prefer a sentence in plain English that says what we heard.

Pat Maryland – Although we heard that they want care for all, they didn't all say they wanted a single payer. We need to be careful about that.

A clear majority (Therese Hughes – could we use specific numbers in these instances?) *of people we heard from, like the majorities responding to a variety of national polls conducted over the past few years, are in favor of a national system that guarantees health care for all Americans. Others expressed doubts, or strongly opposed, any increased involvement of government in health care markets. There was, however, across the board agreement that overall the current health care system has major problems, or is in a state of crisis.*

George Grob – Do the preceding three paragraphs say what the members want us to say? For instance, there is no mention of continuing reliance on the current system.

Richard Frank – People want to address the problem of the uninsured; we can suggest to Congress that they pick any of the available options in order to do so.

Dotty Bazos, other Members – Don't eliminate the paragraph.

Catherine McLaughlin, Joe Hansen, Dotty Bazos – Modify it; put the private plans as the first example.

Financing Health Care That Works For All Americans

How will we pay for health care for all Americans? This and other of the recommendations contained here call for actions that will require new revenues to provide some health care security for Americans who are now at great risk. The opinion polls we examined, the community meetings we held, and the web based surveys and comments we received, all showed large majorities of people willing to make additional financial investments in the service of expanding the protection against the high costs of illness and the expansion of access to quality care.

Frank Baumeister – This paragraph suggests that new revenues will be needed.

Randy Johnson – How can we make recommendations if we don't know what each will cost?

George Grob – The agreement has been that we wouldn't try to score the proposals but that there would be conceptual detail provided.

Aaron Shirley – Is the cost of the entire package or of individual recommendations the issue?

Don Young – You probably need to acknowledge there will be substantial redistribution of costs.

Dotty Bazos – People we heard from were asking for better use of money already being spent; they know we already spend more than any other western nation. However, they weren't asking for huge increases in spending.

Catherine McLaughlin – Start with the second paragraph; begin with what Don Young talked about first. Emphasize moving money around and only then talk about new money. We don't just see large additions of money; rather we should emphasize restructuring. Rewrite how this section starts.

We recommend adopting financing strategies for these recommendations that are based on principles of **fairness, efficiency, and shared responsibility**. These strategies should draw on dedicated revenue streams such as enrollee contributions, income taxes or surcharges, "sin taxes", business or payroll taxes, or value-added taxes that are targeted at supporting these new health care initiatives. ***Another funding option would be to change the rules that now give both employers and employees a Federal tax subsidy for employer-sponsored health care, and use the additional tax revenue to help pay for broader coverage. For example, Congress could cap payroll tax exclusions at the average cost of group overage for full time employees.*** **(bold, underlined text above was suggested, and approved, by vote, as noted below, by the Working Group, during the meeting -- per Jill Bernstein's comment that the Presidential panel only had the employee income tax portion.)**

Don Young – Do you intend to include both the employer and employee? If you do away with it for the employer, it will be another pressure for employers to not provide insurance.

Joe Hansen – I'm opposed to an employee mandate without one on the employer. If we're talking universal, we need to define what it means. Doing this doesn't make it clear what we are doing to affect access, cost, and quality.

Catherine McLaughlin – To be clear, as we are discussing, this would not be part of the recommendation, it is part of the discussion/options/rationale. To not include it would make the Working Group look uninformed. If it is going to be a recommendation, we are taking a stand on a particular approach.

Richard Frank – We are talking about capping, not eliminating here. It raises revenue and encourages employers to focus on more efficient or at least lower cost plans; that may be the only explicit thing we are doing to control costs.

Joe Hansen – That makes it a cost shift to employees. Simply changing the caps may still result in both the employer and employee paying more.

Richard Frank – The cap would change the way people thought about the issues. Say I have a pretty much tax-subsidized plan. Between an HMO and point-of-service plan, I'd choose the HMO.

Therese Hughes – Capping the tax subsidy would accelerate providers not continuing to provide certain services under some insurance plans.

Don Young – The hope of those who favor caps is that it will make people more cost conscious.

Joe Hansen – If we're going to do this, the savings need to go back into the health system, not into the general revenue of the Treasury.

Richard Frank – That's an important point; I agree with that.

The Working Group Voted, 8 to 2 with one abstention, to add the new language (in italicized black bold above) reflecting Jill Bernstein's draft edits.

Therese Hughes – "Efficiency" is not a word that every one understands; we need to use another word. (No consensus reached on this.)

We note that improvements in efficiency through a variety of mechanisms such as investments in health information technology, public reporting, and quality improvement, may be realized over time. To the extent that such efficiency gains are obtained they would be used to assist in paying for new protections recommended here such as those against catastrophic health care expenditures and the impoverishment of individuals as a result of getting the health care they need.

[Add something here on whether this will cost a whole lot more, or move money around, or provide a better platform for addressing the major problems of rising health care costs/ paying for health care that is facing every nation. (This material will be added by staff to reflect Working Group discussion of this subject)]

Catherine McLaughlin – Some language such as this is needed; some of the cost will result from moving money around.

Joe Hansen – People were willing to add money to pay for the coverage and that needs to be included.

Richard Frank – The cost of broad coverage will be tens or hundreds of billions of new money. We should not be disingenuous; we should be out front about the fact that there will be added costs.

Frank Baumeister – We were charged with addressing the problem of high costs and I'm worried about having recommendations that start with saying that we need to spend more.

Therese Hughes – The recommendations need to be forthright about potential cost.

Randy Johnson – Is there enough concern about increased costs to say that we will modify our recommendations to keep them tax revenue neutral?

Joe Hansen – We can take some steps to address health care problems, and that will cost more money; or we can control costs by not recommending that we do much.

Catherine McLaughlin – The American public isn't really willing to give up very much; there are a lot of people out there who say that even if it costs more money to provide broader coverage, so be it. A lot of people won't be happy with only core benefits. There may be an inconsistency between what we are spending and what American people want – an inconsistency that Americans collectively don't understand.

Therese Hughes – We've put the cart before the horse by coming up with recommendations before we knew where the financing is going. There are a fair number of people who think we're already spending enough. We need to put that in the report.

Dotty Bazos – There are two issues: coverage for everyone which will cost something and rising costs as we go into the future; isn't that the more dramatic concern? Can we separate the two issues?

Catherine McLaughlin – Do you use the budget neutral lever to exclude people or benefits (as heard in Oregon)? The people on the quasi-governmental entity have to bite the bullet of appropriated funding.

Montye – The public wants it all and someone else to figure out how to make it so.

George Grob – There are several conventional approaches: decide how much to spend and ask staff to design a way to do this; provide for an escalating/phased-in budget; start with a design and exploit the opportunities that come along; and to the extent that there are administrative/efficiency savings, expand program as funds become available.

Catherine McLaughlin – Our approach is starting with catastrophic; we thereby address a basic need for everyone, as an initial shot across the bow establishing the concept of universality. The core benefit proposal then follow.

Richard Frank – The only way you can make the $1.9 trillion cover everything is that you have to have a lot of control over the entire system and significantly limit the benefits and that is not the case and is not what is being considered by this Working Group.

Dotty Bazos – What we're really doing is adding more money for the uninsured. We haven't done anything to address the fragmented system.

Frank Baumeister – In the current climate, if the first thing we say is, 'we want some more money' then it will not be well received. We need to be able to say: we're going to need some more money, and here's why.

Catherine McLaughlin – It doesn't have to require more money; that's a decision the quasi-government entity is going to have to make.

Richard Frank – There are a number of ways to come up with funding: use Medicare to use its purchasing power, which could have profound effects; or use an integrated public health network/infrastructure, capping tax exclusion of employer provided health benefits. Unless you have major national/international events, you don't get Congressional action to move around 17% of the economy. We need to say that we see a need for new revenue and then suggest our favorite five ways to come up with the money.

Jonathan Ortmans – And then add language that the WG hopes that over the long haul there will be savings from greater efficiency?

George Grob – Summarizing morning's conversation: revising the financing paragraph

- Some money can be moved around
- Some added money will be needed in the short run and, potentially, in the long run
- Some money can be saved from increased efficiency, HIT, streamlining, and so on.

No specific health care financing mechanism is optimal. We understand that the transition from the current system to a system that includes all Americans will take time and that multiple financing sources will need to coexist during the move to universal coverage. However, the disparate parts must be brought together in a way that ensures a seamless and smooth transition. *First do no harm. Careful attention will also need to be given to current government programs and participants in these programs. More than one quarter of all Americans currently have health coverage through government programs, including Medicaid, Medicare, SCHIP, the military health care programs (TRICARE programs for military personnel and their dependents and military retirees, and VA programs), the Indian Health Service* (Therese Hughes – add "and their trust agreement with the Federal government")(not specifically agreed to by the Working Group), *Federal public health programs, and state programs. These programs have been designed to meet the needs of different populations and represent specific forms of public commitment to the populations covered by these programs.*

Catherine McLaughlin – I'm not sure about leaving everything in place; we're trying to change the system.

Randy Johnson – Where is the mention of employer-based insurance? The way this reads now seems like: "we're not going to do anything to harm these government programs but we could care less about the private sector programs." The whole system may suffer if we move toward more government-run systems. The catastrophic coverage proposal "incents" employers to discontinue employer-sponsored coverage.. There are a lot of plans that would say it costs them too much to keep providing coverage.

Dotty Bazos – As we go forward, there is the notion that some of these programs should no longer exist.

Aaron Shirley – We could change the emphasis to make the focus on doing no harm to the individuals that are covered by the plans.

Joe Hansen – I'd like to see the list of employer systems that would be harmed so I could debate it or rebut it.

Deb Stehr – There's stuff in Medicaid that no one will cover (respite care, etc.). These affect the family members, single women, people that do those direct care jobs since Medicaid is the funding stream. We need to spell out that people under current programs are going to be protected or it will cause panic and distress.

Catherine McLaughlin – It just can't be that the same amount of money is going to be rearranged to cover more and more people without someone losing; it may be the people who are "over-insured" or hospital CEOs or "profit mongers."

Therese Hughes – It is indefensible that harm will be done to people who are at the bottom rungs of the ladder. If we remove these government programs, we will be looked at as harming the most vulnerable. It would be wrong not to protect them.

Randy Johnson – The paragraph "screamed" that the 160 million people under employer-based health insurance programs won't be protected from harm.

Aaron Shirley – Maybe the language needs to be clear that we are protecting everyone, with special attention to the vulnerable.

Catherine McLaughlin – But, we may harm some; if you redistribute a fixed pot of money, you may harm some. I'd like to emphasize the needs of individuals rather than the systems or the programs. We want to protect people as individuals, rather than as members of a categorical program.

Aaron Shirley – These programs fill in the space between the American dream and the conditions of people who have nothing. I don't think that a statement that we want to take care of

the most vulnerable comes across as ignoring or negating the needs of those covered by employer-based system.

Pat Maryland – I'd prefer that we provide for an "appropriate level of safety net" for each person as we move toward a universal/integrated system.

Frank Baumeister – But we do hear that some people have special needs.

Therese Hughes – By protecting a program, until a universal system is in place, we are providing support for the most vulnerable.

Montye – There are very wide divergences from state to state across Medicaid programs.

Jonathan Ortmans – What about getting language in the recommendations about protecting the vulnerable populations rather than about protecting the specific institutions and remain silent on the institutions? This would underscore the change in paradigm you are seeking.

Montye – What about all the people that are falling through the cracks in the current system?

Therese Hughes – It's not enough to only talk about the populations, I'd rather have a program in place to protect the people in some way. To not mention the programs is to make it appear that we are ditching them.

Frank Baumeister – We need to retain as much as necessary to ease the transition but we need to emphasize and move toward a better future system.

Randy Johnson – On the subject of Medicare; many feel we need to get it on a better funded basis. Are we intending to have any comments about how to change Medicare to improve it for the future? Are the benefits to be improved; will the age of eligibility need to be increased? Is that something we'd like to explore?

Richard Frank – I think we are trying to say that "if we go to a universal system we are concerned that very vulnerable persons may be harmed and we want to avoid that."

Working Group Voted on whether to specifically mention the programs or to remove mention of the specific programs (and incorporate some of Richard Frank's language)(and continue not to mention private/employer-based programs). Only 5 voted to mention specific programs; 6 voted to not mention specific programs.

Staff was asked to work on some alternative language that focuses on protecting vulnerable individuals rather than programs.

The structure of benefits, the ways that services are actually delivered, and the payment mechanisms differ from program to program, and in the case of Medicaid, eligibility criteria vary substantially from state-to-state. Each of these programs is part of the web of health systems and plans that serve communities throughout the United States. We heard a lot about

how vital these programs are to many of those attending the community meetings, and heard a lot of support for building on public programs to help expand access to care.

If major reforms to the current health care system are enacted, the role of current Federal and state health care programs will need to be reassessed. It will be critically important to ensure that the special needs of the populations now being served by public programs continue to be met. It will also be important to make sure that any changes made to coverage or benefits make it easier, not harder, for people to get the care they need.

Recommendation 2:
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.

- Health care 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.

Rationale

Participants at the Working Group's community meetings nationwide recognized that the process of sorting through what should be included in a basic health package, and what might be optional, or left to individuals to pay for entirely out of pocket, would be very difficult. Discussion groups at the community meetings strained to come to any consensus about what types of services would be "optional", in part because different people value services or types of care differently. Discussants pointed out that some services may be more important for some segments of the population than others, such as children or the elderly, or those with particular types of health problems. What might seem optional for some may be viewed as essential for others. This often led participants to conclude that a broad set of services should be covered. There was a general recognition, however, that there needs to be a structured process for determining what benefits should be included in the core benefit package. In meetings throughout the country, the majority of participants consistently told us that consumers should play a major role in this process, along with medical professionals, Federal government, state and local government. Some participants indicated that employers and insurance companies should also play a role, but one that is more limited.

Discussion

[Add something here about how this recommendation is directly linked to Recommendation 5 because core benefits need to be based on medical evidence.

- Private-public group that will allow full participation of consumers.
- Operations are transparent and, therefore, less prone to political influence.
- Needs to have sufficient resources, and adequate and stable funding.
- How decisions will be made to only include benefits with proven effectiveness may need to be specified. The Medicare program has struggled with this issue for a long time. It

may have to be specified in statute to provide the authority to not include popular benefits in the core package.

(This material will be added by staff to reflect Working Group discussion of this subject)]

Recommendation 4:
Support integrated community health networks.

The Federal government will lead a national initiative to develop and expand integrated public/private community networks of health care 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 health care by:

- Identifying within the Federal government the unit with specific responsibility for coordinating all Federal efforts that support the health care safety net;
- Establishing a public-private group at the national level that is responsible for advising the Federal government on the nation's health care 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

Aaron Shirley provided an explanation of background for this third bullet. He explained that Federal tort liability protection, cost-based reimbursement, and reductions in the cost of prescription drugs are generally available only to Federal community health centers, but that these authorities could be very useful to other community-based groups who try to assist the underserved.

Members agreed (by general assent, not recorded vote) to leave the language of the bullet as is, despite a letter from the National Association of Community Health Centers objecting to the bullet.

- Providing Federal support (Catherine McLaughlin – Does this mean make dollars available?)(Therese Hughes – The free clinic needs the tort coverage. However, most free clinics would not take Federal grants; they don't want the hassle.) for the development of integrated community health networks to strengthen the health care infrastructure at the local level, with a focus on populations and localities where improved access to quality care is most needed.

Pat Maryland – There is a need to raise the bar of what community clinics provide.

Catherine McLaughlin – We wanted this recommendation to be a magnet to create care that is new and innovative. Instead of having all the separate entities have to compete, make it a more integrated system.

Richard Frank – The Ascension model would create special districts and bring all the local health participants to the table. So, one approach is to loosen the rules for any group willing to do this.

Pat Maryland – The model works because groups are willing to bridge between and across their systems.

George Grob – Is the Working Group proposing to authorize funding or additional help to those communities willing to do this and are there are local dollars that will come to the table to assist in carrying this out?

Therese Hughes – All the rest of us compete at the local and state and private foundation level; this would provide some funding in case those other sources weren't available.

George Grob – Are we proposing, in addition to making more entities eligible for 340B, Federal Tort Claims Act coverage and Federal grant funding, increasing Federal funding? Or are we saying we would go in and tap the FQHC core money? If we are saying that we wouldn't tap the existing money, some objections raised by NACHC might go away.

Aaron Shirley pointed out that the proposed language talks about "expanding" as well as "modifying" the concept, implying the possibility of a budget increase (without explicitly saying so).

Dotty Bazos advocated modifying the requirement for community representation on the boards.

Pat Maryland – The rationale needs to reflect that although there are 14 million beneficiaries, there are over 50 million eligible who are not being served (there is about $1.7 billion funding for Community Health Centers, about 900 Community Health Center grantees with about 3,700 sites).

Rationale

At the community meetings and on-line we heard stories about the difficulties many people, especially those who are low-income and/or uninsured, have in what our meetings called "getting health care." A lack of primary care providers; inability to access specialty care; and difficulties in navigating a complicated system, especially for those with chronic conditions, were among the problems cited. "Fix the delivery system first," was the closing comment at one community meeting. At the same time, we heard strong support for neighborhood health clinics. At community meetings, expanding these clinics consistently ranked as the second or third choice as a proposal which would help assure access to affordable health care services and on-line 84 percent of respondents either agreed or strongly agreed with this approach. We also heard support for strengthening the health care safety net for those in need both through the on-line poll and at community meetings. In both cases, about three quarters of respondents expressed support or strong support for expanding neighborhood health clinics.

Discussion

Health care coverage alone does not assure access to services, particularly for low-income individuals, those with chronic conditions whose care requires coordination, and those facing additional challenges such as geography or language. Many people rely on the health care safety net for needed services. The organization and delivery of care for vulnerable people is, moreover, very much a local matter, with great variation across communities. Currently, the Federal government provides support to safety net providers in a variety of ways, including programs to help cover the costs of the uninsured, support provided through the Medicaid program for Federally Qualified Health Centers and grant programs for community health

centers, programs providing services to people with HIV/AIDS, and support for medical education programs in children's hospitals. But efforts from the national level to strengthen local safety nets are hampered by the lack of focus and overall strategy for coordinating all the various strands of the "safety net" that provides essential services to many Americans.

We have been impressed by the creativity and energy some communities have brought to improving the health care delivery system for disadvantaged populations. These programs not only provide critically important services to their communities, but they can also play key roles in the development of the health education, care coordination and management, and information technologies crucial for improving the health care system that we propose in Interim Recommendation # 5 below.

We want to encourage these efforts with Federal support, but we also recognize the significant challenges in designing our approach. First and foremost, we want our efforts to support a fundamental reworking of the organization and delivery of community health services. The goal is to encourage innovation, but reforms also need to hold new programs and participants in the local health delivery system accountable to their communities and to funders. Reforms will also need to address the chronic inefficiencies associated with applying for and administering grant funds. New approaches that reduce administrative burdens (and costs), and that allow greater flexibility and innovation --in both administration and financing-- need to be developed.

➢ QUALITY AND EFFICIENCY: Intensified efforts are central to the successful transformation of health care in America.

Recommendation 5:
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 health care 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 health care 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 health care 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.

Rationale:
The Working Group heard considerable support for improving the effectiveness and quality of health services. Participants expressed preferences for using medical evidence to decide which services are covered and provided. Many participants discussed the importance of focusing on evidence-based medicine. Many participants also agreed that greater investment in health information technology and moving to an integrated system of electronic medical records could improve administration and treatment and reduce medical errors. More than two thirds of respondents to the Internet poll supported more investment by doctors, hospitals, and other providers in health information technologies as a means to improve quality and increase administrative efficiency; similar results have been found in national polls conducted by other organizations. In the Internet poll, participants overwhelmingly supported the view that the private sector and government programs should improve the efficiency of health care. Participants also expressed general support for individuals having the ability to be informed health care consumers and to be involved in treatment decisions. They expressed a desire to have information about how to use health care better and more effectively. National polls have also shown that many Americans believe they do not have enough information about hospitals and other health care facilities to make educated choices for health care services.

Discussion

[(The following or alternative material may be added by staff to reflect Working Group discussion of this subject.) Important, innovative work is underway in the Medicare program, the VA, and a number of local and regional private systems around the country. This recommendation would use the purchasing power of the Federal government to accelerate progress in improving the effectiveness of health care. In addition to using its leverage to spur innovation, the Federal government could also partner with the private sector to evaluate new systems.

This expanded effort could be coordinated in different ways. One option that has been raised in a number of proposals over the past few years calls for the establishment of a national board, modeled after the Federal Reserve Board, that would provide guidance to the private and public sectors in overseeing health care in America. Such a board could help define policies and strategies for cost management, setting standards for payments and reimbursements, and quality improvement, and monitor access to care.]

The Moderator asked the Members whether they wanted to discuss the option of establishing a national health board (see also Recommendation 2) to coordinate private and public efforts to improve quality and efficiency and, if so, what the relationship between this group and the one responsible for defining core benefits should be.

Randy Johnson – I'd be concerned about this as there are already various other entities in existence that have been working on these issues during the past 2-3 years. It would imply a Federal system to oversee everything.

Montye – We've heard criticisms that it seems like we would be creating more bureaucracy.

Frank Baumeister – There a number of entities that are already looking at quality.

Moderator – Some felt that this group would be quasi-public and therefore could make it a beneficial addition.

Joe Hansen – There ought to be an entity monitoring costs.

Pat Maryland – Having a mechanism that is non-Federal to monitor cost and quality would be a plus.

Dotty Bazos – There aren't national standards at present for quality. There needs to be some institutional mechanism to link core benefits and costs to assure that costs don't rise unnecessarily and quality is monitored and improved.

Catherine McLaughlin – Maybe it's the wording, a "Federal Board: does sound like big brother.

Don Young – Entities like ProPAC ("Prospective Payment Assessment Commission") and MedPAC ("Medicare Payment Advisory Commission," which consolidated ProPAC and the Physician Payment Review Commission) comment on and monitor Federal program actions; that's quite different from establishing an entity to monitor the private sector.

Dotty Bazos – There's no mention in this current section regarding the private sector and quality; somebody's got to be looking at the whole piece.

Randy Johnson – The private sector has been driving it and would be opposed to a Federal take over; and CMS and AHRQ are at the table regarding quality and efficiency.

Catherine McLaughlin – In the rationale, there should be something about the Federal government rewarding programs for acting on this: use the money to reward the private sector initiatives. The other part of the private sector role is that the individual has to be a good steward; we need to say something about the public being behind this; they want to see efficient use. The rationale should say that the public wants this. The public is on board regarding health education, electronic health records, etc.

Richard Frank – The discussion could address the mechanisms to achieve quality and efficiency.

Catherine McLaughlin – We want the Federal government to use its leverage to encourage this.

Pat Maryland – I like the idea of acknowledging the role of the private sector.

Catherine McLaughlin – Underlying efficiency and quality is cost.

Randy Johnson – The American Medical Association is working with Congress on pay-for-performance. There are a number of legislators willing to allow better performers to earn more. CMS is working on demonstration projects on this.

Dotty Bazos – Put Medicare in charge, within the Federal government, of promoting quality and efficiency.

Jonathan Ortmans – Everyone appears on the same page but not in agreement on establishing a "command and control" big government role.

Joe Hansen – We heard a lot that the system ought to be simplified. If we did electronic medical records, it would address both quality and cost. If we wanted to advance this objective, we might want to revise the proposals along the lines Dotty Bazos is suggesting (e.g., putting Medicare in charge of promoting quality and efficiency).

Pat Maryland – I think we need to encourage all these initiatives and Medicare can start this process; transparency should be encouraged.

The Moderator suggested that Members Email the Executive Director comments, for staff incorporation in a revised document.

Dotty Bazos – Who is advocating for a strategic approach to helping us grow a system to develop ways for improving HIT locally, benchmarking, etc.?

Richard Frank – If Medicare changes, other institutions will to.

Randy Johnson – There are already a variety of private organizations that are banding together to work on pay-for-performance, quality standards, etc.

Recommendation 6:

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 health care system to understand their health care 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.

Rationale

Care at the end of life has surfaced at virtually every community meeting as a concern which encapsulates many of the frustrations with health care in America. We heard that such care is expensive and often "futile," is too often based in hospitals and nursing homes, and may not comport with the wishes of the ill person or his family. At the community meetings we heard a clear endorsement of limiting coverage (Richard Frank and other Members voiced the opinion that the trade-off between coverage for end-of-life versus in-home comfort care was a false dichotomy. They indicated that saying "coverage" is a very blunt policy instrument. They suggested using language to indicate that unnecessary care should not be paid for.) *for end-of-life interventions of questionable value in order to provide more at-home and comfort care for the dying. This idea also received strong support in both the Working Group Internet poll and the University town hall meeting, where 61 percent and 63 percent respectively either agreed or strongly agreed with the proposal. This dissatisfaction with care people receive at the end of life that we heard at community meetings echoes the sentiments of a 2002 national poll which found that six in ten respondents gave the current system a rating of fair or lower. Three quarters of those surveyed believed that the current system found the current system fair or worse at assuring that families' savings are "not wiped out by end-of-life care."*

Discussions at the community meetings, and, in particular, the one meeting devoted to end-of-life issues held in New Hampshire, underscored the need for rethinking how care at the end of life is delivered and financed so that this care incorporates the values Americans say are important to them, including honoring personal choices, good pain relief, and being treated with respect by health professionals. Payment incentives now are misaligned: they encourage heroic interventions and care in institutions, and do not encourage physicians to spend time talking to patients. In New Hampshire, we also heard about the important role non-medical services play at the end of life.

Discussion

Aspects of the three preceding recommendations are especially salient in considering care of the dying. It has been estimated that last year-of –life expenses constitute 22 percent of all medical expenditures and a major fear for many people as they approach death is the financial burden their care may place on their families. There is a critical need for new models of care delivery that do a better job of piecing together the support and community-based services (which often are non-medical) that the dying and their families need. And, a greater emphasis on health care quality—a stronger focus on knowing both "what works" and when medical intervention serves no good purpose care—coupled with more consumer-friendly information and better provider-patient communication—will help the seriously ill make more-informed choices about their care.

Helping Americans have the "good death" they desire will require change. The starting point for the fundamental restructuring we envision is for Americans to think about their wishes for their own end-of-life and make their views known to their family and health care providers. At the policy level, care models have to address the longer lives people are leading and the often extended periods of fragility; payment for hospice services need to be revisited to better account for the most common patterns of death and dying; payment for providers needs to be less procedure-driven and take into account time spent talking to patients; and care for the dying needs to be a central component of training for all health professionals who have direct contact with patients.

The Moderator asked whether more definition of "futile" care and cost-effective end-of-life care was desired by the Members. No one answer was provided although there was general agreement that some revision to the wording was needed. Staff was asked to develop appropriate language.

-----[This ends the portion of the summary using a color-coded format.]-----

The Working Group adjourned its first working day at 5:16 p.m., Wednesday, June 21, 2006.

The Working Group reconvened at 8:30 a.m., Thursday, June 22, 2006.

[NOTE – In the following, some Member comments are summarized and others paraphrased; they are not direct verbatim quotes.]

Randy Johnson – The Working Group received a call from Seabury Davis who wanted to talk to the Working Group. The Chair contacted him and told him that the Working Group was not meeting with vendors or stakeholders in general, but that he (Randy Johnson) would talk with him briefly over the phone. In that conversation, Randy asked that he submit any comments for the Working Group's consideration in writing, which he did. A document that Davis provided was passed out to the Working Group.

Catherine McLaughlin concurred with the Chair's point that the Working Group should consider it the usual practice to ask anyone who wants to provide comments to do so in writing so it can be a shared document rather than something a Member handles on an individual basis.

The Working Group VOTED 8 to 3 against including a recommendation to have an overarching board to improve quality and efficiency.

Dotty Bazos commented that there had been discussion to have the board also address cost issues.

The Moderator indicated that some Members wanted to revisit the question of whether the Interim Recommendations would continue to include dates or an implementation timeline.

Richard Frank – There must be no additions or changes by staff that are not approved by the Working Group.

Randy Johnson – If our intent is not to give the staff discretion then we need to build in time for our process to address what we want.

Jonathan Ortmans – Do you want to make any changes to the materials now?

Richard Frank – We've created an impression, especially on the timing. We need to change what's on the Web site. The three "arrow" headings are not recommendations.

George Grob – The major work on the Final Recommendations will be in August; at the final meeting suggested for the end of September, we can only make minor refinements and after September 31, the recommendations really can't be changed at all. Apart from the introduction, the financing section, and the three arrowed banners, the remainder of the material can't be changed during the comment period.

Catherine McLaughlin – I'd like all three banners out. The media has grabbed those banners and they have caused us trouble. I don't see a need for them.

Montye – People have literally tossed the recommendations aside when they saw the date 2012.

George Grob – I'm prepared to make the changes recommended, including removing the banners. We are adding explanatory language. I'd like to suggest that we add a sentence that the dates of implementation will need to take into account the changes recommended – to address the curiosity of the press. This exchange with the public can be a very active one.

The Working Group Members then VOTED unanimously, 11-0 to remove the banners when the rationale is added and mounted on the Web.

Jonathan Ortmans – You agree that an opening paragraph that explains how the proposals fit together would be appropriate?

Members had general discussion about desire for a visual graphic.

Frank Baumeister – I want the catastrophic proposal to be first and the safety net recommendation second.

Catherine McLaughlin, Joe Hansen and Frank Baumeister discussed the need to change the order of the recommendations.

The Working Group Members then VOTED 10-1 to revise the order of the posted Interim Recommendations to make it (based on the current numbering): 3, 4, 5, 6, 1, 2.

The Moderator suggested that another topic for discussion, mentioned previously by Members was the need to have an emphasis on the mainstream, the middle class, and not just special populations.

Other concerns and comments regarding tone or style that Members expressed included:

Deb Stehr – Having the proposals be in plain English is valuable.

Frank Baumeister – I'm still unsure about the financing piece and the catastrophic proposal.

Pat Maryland – The more precisely we present this the better it will resonate with the public. Whatever rationale and documentation we can provide will help support the recommendations. We've had a lot of internal controversy about the validity of the basis for the recommendations so any outside/independent data/validation that sheds light on our recommendations, rationale, and discussion would be helpful.

Richard Frank – We ought to emphasize principles and values. Our tone ought to tie our ideas to what we heard, why we believe they are feasible, and model our recommendations on other examples that have been used successfully before. There are a lot of rule makers and technical people who will take what we do the next steps; we want to put them on the right path.

Randy Johnson –Earlier I indicated that I would like some time to formulate my response for regarding my reasons for believing that which I believe the catastrophic coverage would be

harmful to the employer-based health insurance system, and I am open to discussing this topic whenever the Working Group would like to do so.

Joe Hansen – We ought to be concise. I want to revisit – with the financing committee – the possible recommendation/statement on this topic. I'm also concerned about Randy Johnson's public statement that he is opposed to the report. I don't know how he can say that and still be Chair of the Working Group.

THERE ENSUED A DISCUSSION OF THE ROLE OF THE CHAIR IN REPRESENTING AND LEADING THE WORKING GROUP IN LIGHT OF HIS DISAGREEMENT WITH THE RECOMMENDATIONS.

Frank Baumeister – I do not want the time, energy, and successful efforts the Members have expended to date to be wasted. Whoever is Chair must be able to compromise his personal views and background, in recognition of the general agreements of the large majority of the Members; if he is unable to do so, I believe that the individual needs to recuse himself from the process. The current incumbent has been unable to modify his opinions from the outset of our work and has not been willing or able to acknowledge or accept the legitimacy of what we are hearing from the public. This state of affairs is incompatible with either continuation of the current leadership arrangements or else my continued participation in this Working Group; something needs to change.

We need clarification of whether the Chair intends ultimately, at the end of this process, once we have submitted our Final Recommendations to the Congress and the President, to publicly disassociate himself with the consensus findings of the Working Group and to actively dispute them. If this is the Chair's intent, then I would have to consider appropriate actions.

Randy Johnson – I've said in the past that I've had concerns. One thing I haven't tried to do is influence the staff. In the early stages I shared my perspective. The Working Group has agreed that the Members should have equal access to work that is done. For months I haven't seen anything that you haven't seen from the staff. I do have a different perspective on the recommendations. Anyone in the Working Group can speak as they feel appropriate. As I said in a recent email, I can't support the recommendations. If you want to call that obstinate that's your prerogative. I have no intent to sabotage the process but to represent with integrity, as have you, my views.

Catherine McLaughlin – The Chair did send an email to Senators Wyden and Hatch and to David Walker, about the Chair's inability, personally, to support the recommendations. We did discus how we would handle minority reports. When I saw the Chair's email, I concluded that the Working Group needed rules about how to deal with this. Brent James, for example, said in his radio talk that "I stand behind these recommendations." I think everyone except the Chair has compromised on the agreed-upon set of Interim Recommendations; all of us have things near and dear that we've given up to get to the greater good. But the Chair has not. Is anyone else intending to write a minority report, a dissension? What is the Working Group's plan? How do we respond to the Chair's email? I think it means that the Chair cannot be a spokesperson for the

Working Group. What is the Group sentiment; the Executive Director needs the group's guidance on this.

Randy Johnson – I have not responded to the Press since the Interim Recommendations came out, intentionally. There have been unfair allegations that I misrepresented the group in Cincinnati; so I've chosen not to speak publicly. I think you are right; I can't be the spokesperson for the group if I dissent from the report. Early on it was clear the Working Group could outvote anything I would recommend. Dotty Bazos suggested a statement (of dissent) could be included in the final report.

Joe Hansen – I think you are in a difficult position, Randy Johnson. As the Chair, it's your obligation to support the recommendations. You are different than the rest of us; holding personal and public views are different.

Randy Johnson – It's the prerogative of the Chair in most organizations (Congressional committees, Deans of a school, any committee) to express views.

Richard Frank – Those are the wrong analogies, we are more similar to MedPAC, an IOM committee or the committee that oversaw the Veterans Administration's decisions on Prozac. These engage in consensus processes. We operate in many of the ways they do. It's interesting that the Chair didn't bring any of those examples up. They too are made up of diverse individuals as is this one and most of the time they manage to work out the differences.

Dotty Bazos – I'm personally disappointed we haven't gotten "bigger," but I'm willing to listen and compromise and take first steps to move the system ahead. I've compromised a lot, but I have no mal-intent. In his comments yesterday, the Chair stated that every one of the Working Group Members has intentionally written recommendations to harm employer-based employees. The Chair, in his personal opposition, is a tremendous barrier to the public accepting these recommendations. I think it unfair that the Chair does not play his cards honestly. The Chair is a bigger obstacle than the Congress.

Randy Johnson – I've tried to communicate as best I can; I don't know how I could have done differently.

Richard Frank In general in our deliberations, we've been pretty good about letting the arguments have the day. Every time people have challenged the Chair to explain his positions, he has never done well explaining his rationale. The answer is always "I'll get back to you on that." To come in here (three months before the Final Recommendations must be issued) on June 22, and say you still haven't articulated them is "a dollar short and a day late." The least the Chair could do is make his argument; that's the most the other Members can ask; then vote any way you want. If you don't put your rationale on the table: game over, I've found that very frustrating.

Randy Johnson – I've tried to be as explicit as possible. I am not from the same environment where I deliberate issues the same way other Members of the Working Group do. I've attempted to share as effectively as I'm able to.

Joe Hansen – I don't know what the Chair means about not coming from the same environment regarding how deliberations are carried on. What's so different about the Chair's personal/employment environment? I could jump to the conclusion that it's the George Bush environment.

Catherine McLaughlin – What are the implications of the discussion, what are the concrete issues? What do we do about the minority report? Can the Chair just write it and send to editors? Does it become part of the report? What limitations need to be placed on it?

Dotty Bazos – If you, Randy Johnson, continue to be Chair, then it needs to be part of the (Final Recommendations) report in a standard and agreed-upon way. Can anyone just leave the committee and write whatever they want?

The Moderator suggested that the Members needed to determine how to proceed and how to communicate personally and publicly. Members will not agree on everything; they have to speak their individual consciences. The Working Group can set an example for the country as an "orchestra" and:

- Focus on different tunes;
- Focus public comments on recommendations Members can support;
- Emphasize the need for consensus and compromise; and
- Challenge America and the current health care system to make the same compromises for the greater good.

Aaron Shirley – A blanket statement that the Chair can't support the recommendations would be an indictment of the entire committee coming after all the deliberations and compromises. Here we have 13 Members that have agreed and one individual saying he can't support the recommendations; it's an indictment.

Catherine McLaughlin – The Chair's email indicated that he didn't agree with the Interim Recommendations and that if he wasn't able to get the Working Group to change its recommendations that the Chair would write a statement indicating his disagreement. I don't think the Chair can be George Grob's boss anymore if he formally opposes the recommendations. I don't think he can be making budgetary decisions for the remaining efforts. There are issues such as how final testimony is prepared, how funds are spent.

Randy Johnson – Recently, I've tried to leave virtually all the decision-making to the Working Group. I'd discussed bringing up the topics you (Catherine McLaughlin) are listing with the Working Group in August but having this come up today is fine.

Therese Hughes – I see no reason at this stage to restructure the committee. I am in a minority position, having decided to speak for disadvantaged groups.

Joe Hansen – (Addressed to the Chair): Was your answer "Yes," you will file a minority report, if you don't agree with the recommendations?

Randy Johnson – I wouldn't take any actions based on what's been said today. However, a person would be foolish not to consider all the comments they received. At this point I don't believe I can support the Working Group recommendations; therefore, there are some tactical decisions to be made regarding who testifies and how to handle responses to the Press. My intent has been to come to the August meeting regarding the subject of how to provide further comments. There are some issues the Working Group may want to give further thought to: what I write; do we call it "minority opinion" or "a member statement"? I'm not sure which approach is preferable.

Aaron Shirley – I'm sure we're all aware that the task of persuading this country of the need to do something is difficult enough. If the Chair dissents to the recommendations, the whole effort is negated. If our recommendations were as radical as I would have preferred, that would be one thing; but I can't see how anything we are recommending are so out of sync that the Chair would be willing to see it go down the drain.

Randy Johnson – Clearly it's better to have a unified approach.

Dotty Bazos – There are two issues to deal with: one is leadership. It is difficult to go forward with a sense of security if the leadership of the group is threatening the effort. Can the Chair really and should he lead the group to the end of the day? I have no confidence that he should. If he was just a member, that's another matter. But since he is the Chair, we need to differentiate these two issues.

Randy Johnson – It's unlikely I'll change my views.

Dotty Bazos – Why don't you recuse yourself and let someone else act as Chair?

George Grob – I've called senior staff of other groups about how they handle dissenting views – MedPac, IOM, ProPac. IOM does include individual Member's views: staff helps write them. Others have avoided the need for alternative statements by elaborating on their discussions of recommendations. GAO offered the model of a one-page statement by any Member, but never actually needed to use this approach. Ours is a unique situation due to the fact that the dissenting Member, Randy Johnson, is the Chair.

Don Young – In ProPAC, it was handled by incorporating language along the lines of: "a consensus, but not all Members, supported the recommendations," and then included the alternative perspective where appropriate.

Randy Johnson – The law says the Comptroller General appoints the Chair; the Working Group doesn't have the authority to take away the position. There have been and would continue to be various informal ways of handling work. There are a lot of dialogues between Working Group Members and the Staff.

Frank Baumeister – We're at an impasse.

Therese Hughes – If the whole group votes 13 to 1, how are we at an impasse?

Frank Baumeister – The Working Group is being held hostage by the private deliberations of the Chair until the end, at which point he will come out from behind the clouds and expunge the group's efforts. I would like the Group to consider a vote of no confidence.

The Moderator indicated that the group would like to have a Chair that they believe is supporting their efforts – a vote of "no confidence" would send the message that the group objects to a Chair who cannot support the results of the group's work.

Catherine McLaughlin – There will be numerous efforts to present and sell the report to the public and someone is needed who can support the work of the group.

Randy Johnson – My differences are intellectual, on a policy basis. I've repeatedly told the Executive Director not to show me the materials being prepared for the Working Group (until they are shared with all the Members). My intent was to do my best and not stand in the way of your recommendations as long as I can make my own recommendations.

Frank Baumeister – I find that unacceptable intellectually, policy-wise; we need to get out of this trap in leadership.

Catherine McLaughlin – I thought it was just a minority opinion now it seems more.

Dotty Bazos – Why aren't we debating the Chair's personal recommendations like we are mine; why not debate them and argue and then reach some agreement?

Therese Hughes – I find it difficult as well that we find ourselves in this situation and understand it is a personal issue, policy issue, and political to a degree. It would be a better idea if the Chair would say "I am going to do this." It would be better for the whole group, and not just for a minority appeal. I think it is important that the Chair articulate what ideas he holds, especially so he can state those that we can agree with as a group. I think the Chair is going to inadvertently shoot himself in the foot if he can't state what he can do. There is no shame in a minority opinion. There is a desperate need to see those skills that caused David Walker to appoint him as Chair of the Working Group. I'd like the Chair to do this for us today.

Randy Johnson – I've shared my perspective in earlier and recent email messages and if you want me to resend these messages to you, I will. I sent email messages in September, October, and early May. The thoughts in those emails come pretty close to expressing my concerns. I'm not "holding all my cards." One of the messages included a power point presentation.

Therese Hughes – The Chair needs to articulate whether he is going to ask for his perspective to be in the report so we can consider that; and whether he is going to do it publicly or privately. The Working Group Members need to know that.

Richard Frank – Our options include leaving everything in place, de jure, while moving ahead to get things done and giving George Grob someone or a group to deal with to move ahead.

Aaron Shirley – I'd like to see the six recommendations on the screen and then someone explain to me why anyone can't support those recommendations.

Frank Baumeister – We can't move forward if we don't have closure on this issue.

Catherine McLaughlin – There are some issues that need to be addressed, including:

- There are some contracts for which there is some money available; how will that be handled?
- Jon Comola was asked to co-facilitate our upcoming meetings; that wouldn't be a good use of resources.
- Craig Caplan (a research staff member) is leaving and his role has been essential; Jill Bernstein (senior staff research analyst) needs additional staff support;
- Get money back un-obligated funds from Wye River and America*Speaks* and use it to pay salaries for needed research staff.

I don't have confidence in the Chair's views representing those of the Working Group. I recommend we call for a vote of no confidence so we can move on. (Seconded)

Joe Hansen – If we have recommendations, the Chair will be called to testify and would then not be supporting the recommendations. That being so, we'd be dead in the water. It would finish us. Don, tell us if you don't agree.

Don Young – I think that's right.

Joe Hansen – The only one who can remove the Chair would be David Walker.

Catherine McLaughlin – When I stepped down, I was prepared to explain that it was personal reasons that caused me to resign. Randy Johnson why, for the good of the group, don't you? It would be the statesmanlike thing to do.

Randy Johnson – My circumstances are different and this doesn't apply. I've considered resigning. I wouldn't do that right now without being asked to do so.

Therese Hughes – I don't think the Chair should resign; it's too late in the game. Knowing Congress, if you can't go forward and present the views of the American people we've heard from, I think we need to ask David Walker to appoint a different Chair. We have to represent, as accurate historians, what we've heard from the American public. I don't think the Chair disagrees with everything. I don't know what the Chair does disagree with.

I think the Working Group needs to ask the Comptroller General to put someone else in as Chair. I can't take the risk of being an inaccurate historian representing the views we've heard.

I'd like to change the motion to say that we go to Mr. Walker and have him understand that we want him to change the Chair.

The Working Group Members then VOTED 10-0 (the Chair not voting) in support of an expression of "no confidence" in the Chair.

The Working Group Members then VOTED 10-0 (the Chair not voting) in support of the following statement: "It is the opinion of the Working Group that the Chair should step down as the leader of the working group."

Richard Frank – There are procedural issues, specifically who the Executive Director reports to.

Catherine McLaughlin –Someone who can represent the Working Group needs to be designated so there isn't a vacuum directing the Executive Director.

Randy Johnson – I am comfortable having others be involved in guiding George.

Catherine McLaughlin recommended that Dotty Bazos do this.

Dr. Shirley indicated that Pat Maryland should also be selected.

The Working Group Members then VOTED Unanimously in favor of supporting Pat Maryland, Dorothy Bazos and Randy Johnson collectively to provide guidance on operational matters to the Executive Director.

Members briefly discussed and agreed by general assent that an expanded Committee on Finance, consisting of Joe Hansen, Randy Johnson, Richard Frank, Catherine McLaughlin, and Frank Baumeister further examine and develop revised language concerning health care financing.

Therese Hughes – Who goes to David Walker?

Members and the Executive Director generally agree that the Comptroller General would be informed by letter, regarding the new leadership individuals and they would be called to notify them as well. The message was to convey that time was of the essence.

Pat Maryland – Maybe we should even meet; we could coordinate that.

Therese Hughes – Whatever changes and amplifications that go on the Web should first go to the Members.

George – Yes

The Moderator complimented the Chair for his composure under pressure about matters he and others felt strongly about. He encouraged the Members to focus on getting on with their work, to look carefully at the documents sent out to supplement the posted recommendations, and to prepare to bring ideas to the next meeting regarding Final Recommendations. There is a procedural challenge the Working Group is facing, but they have significant substantive work ahead of them.

The Executive Director summarized various tentative administrative matters, including: three upcoming community meetings, revising the budget, some issues connected with the "end date" of the Working Group, and final hearings:

- Three Community Meetings are scheduled (EBay in San Jose, July 19, Milwaukee, July 22, Oklahoma, August 1)
- There is $30-50k left over in the budget to be held to cover unforeseen contingencies (bills that may come in, etc); there are sufficient funds available. Also funds for a final gathering, if desired. Members need to decide whether to spend money on attending the final meetings or on a final event. Two working Group meetings already scheduled for August and mid September.
- When the project ends, there are three competing/controlling options: appropriation of funds, the FACA agreement (ends March 25, 2006), or a statement in the Act that says two years from appointment (February 28) and funding. Sentiment among many is that the authorization of appropriations governs – authorized only for FY05 and FY06 9, ending September 30). Many assert that we can't go beyond that. Under this scenario, work would end September 31 except that shut down would be by end of October. The FACA agreement also ends September 30. The expiration of February 28: the committee continues to exist, but at its own expense.
- Who Represents Working Group At Committees – entirely up to the Committees; likely they would set up panels.
- Final Recommendations – The Working Group needs to see clearly that the first meeting in September is really the final substantive meeting.

Pat Maryland indicated she would like to see a budget for each year; and would like to see what dollars have not been spent already before we make a decision about what to do and what is actually spent and what is committed but not spent.

Aaron Shirley – It's good to have ground rules about hearings before we close out; if there is a hearing, there will be people who are not sympathetic to our cause and will seek to discredit us.

Members had a general discussion regarding the August meeting. The sense was that one of the last two weeks of August would work better but that it is important that there be a meeting in August.

The Executive Director observed that the changes being made to the materials supporting the Interim Recommendations should be done carefully and deliberately with at least two "rounds" of comments by the Members; and not to rush the changes.

The Members generally assented to this.

Staff briefly summarized the initial set of (approximately 400) comments received online regarding the Interim Recommendations.

The Working Group adjourned at 1:09 p.m., Thursday, June 22, 2006.