Junior League Notes

Budget

- As you know, involved in a great dabate about how to balance the federal budget.
- This debate is a family issue. Not just a debate about numbers/about our values in this country.

  Do we protect our children and care for our parents? Should we have to make choices between them -- between a college education for our children and nursing home care for our children?

- This debate is NOT about whether to balance the budget. POTUS has shown how to do that in the same time period as the Republicans. Scored by CBO. And he has put forward a plan that is consistent with our values:
  - Medicare -- It secures trust fund well into the future without imposing new costs on beneficiaries.
  - Medicaid -- It preserves the guarantee of quality health care for children, pregnant women and older and disabled Americans.
  - Education and the Environment -- It increases investments in education and protects the environment.
  - Tax relief for working families -- It gives working families a tax cut targeted to education and child-rearing. It does not increase taxed on working families.

Other Family Issues

Book

But is is important to emphasize that -- while I've been talking about the government programs that are designed to serve families -- caring for children and families can't be -- and should not be -- done by the government alone.

On the other hand, as the first lady says in her new book, anyone who has tried to raise children knows that it can't be done by families alone.

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

From: Stacey
Phone: 6-5505

To: Jen

Date: 3/13

Remarks: ① June Walton will call me when her client comes into town (sometime this month).

② ACEP will call when they have a confirmed time + date.

③ No meeting will be scheduled w/ the Underwriters.

3/15 10:00 - 1:00 Meetings

3/17 Gone for day/weekend

~~3/~~ 5/12 - 5/15 Gone for day/weekend

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

JENNIFER KLEIN
6-2599

To: Stacey

Date: 3/7/95

Remarks: Can you schedule RSVP to these for me? Thanks so much!

Starting next week, my schedule is:

3/13 8:30 - 9:30 Speech

3/14 1:30 - 2:00 Meeting

Barbara:

These people call frequently to meet w/ Chris. I've managed to delay the meeting - but they're getting anxious.

Any suggestions?

- Stacey

P.S. The other mtg. I spoke w/ you about is taken care of. (Kohl)

MANATT, PHELPS & PHILLIPS

A PARTNERSHIP INCLUDING PROFESSIONAL CORPORATIONS

ATTORNEYS AT LAW

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January 9, 1995

Mr. Chris Jennings
Special Assistant to the President
for Health Policy
Room 212
Old Executive Office Building
The White House
Washington, D.C. 20036

Western Dental's proposal

Dear Mr. Jennings:

On behalf of our client, Western Dental Services, Inc., I am writing to request a meeting for B. Ray Anderson who will be in Washington this week. Western Dental Services is a state-wide specialty HMO under California's Knox-Keene Act and is one of the largest providers of dental services in California. Headquartered in Garden Grove, Western Dental Services operates over sixty-eight staff model facilities around the state and contracts with over one thousand independent dentists to serve approximately 180,000 plan members in addition to the DentiCal population.

Specialized HMOs bring the same organizational structures and cost-efficient delivery of services employed by full service HMOs to single, specialized areas of care such as dental and vision. Unfortunately, unlike California, many states maintain restrictive laws and regulations that prohibit the formation of specialized HMOs. Providing for federally qualified specialized HMOs can help to contain costs and expand access to health services at no-cost to the federal budget. In fact, specialized HMOs can help to save costs in the Medicaid program as is the case in California. States would continue to be fully responsible for regulating specialized HMOs.

B. Ray Anderson and I would appreciate the opportunity to discuss this issue with you further and will be available to meet at your convenience Tuesday or Wednesday. Thank you for your consideration, and I look forward to hearing from you.

Sincerely,

June Walton

June Langston Walton
Manatt, Phelps & Phillips

American College of
Emergency Physicians

WASHINGTON OFFICE
1111 19th Street, N.W., Suite 650
Washington, D.C. 20036
202-728-0610
202-728-0617 FAX
800-320-0610

February 6, 1995

Chris Jennings
Special Assistant to the President for Health Policy
The White House
Room 213, Old Executive Office Building
Washington, D.C. 20500

Dear Mr. Jennings:

The American College of Emergency Physicians (ACEP) is hosting its annual legislative issues forum in Washington, D.C. and cordially invites you to speak on health care policy of the Clinton Administration and its goals for working with the new Congress. We hope your schedule permits you to address our group on Monday, May 8, 1995, from 2:00-3:00 pm at the Grand Hyatt Washington, 1000 H Street, NW.

As Special Assistant to the President for Health Policy, your overview of health care issues facing the nation, and how the events of the last two years will affect the Administration's health care policy and goals would be extremely valuable. Participants will be most interested in hearing the Administration's health care priorities and their significance to emergency medicine.

ACEP is a national medical specialty society representing more than 17,000 emergency physicians, and is dedicated to improving the quality of emergency medical care through continuing education, research, and public education. Emergency physicians are specialists trained to provide care to patients, including medical, surgical, trauma, cardiac, orthopedic, and obstetric services. Emergency physicians are the only medical specialists required by law to provide care to all who seek it, regardless of ability to pay. This role as "front-line" providers has positioned emergency physicians as guardians of quality, accessible health care for all populations.

We expect over 150 emergency physicians, representing the leadership of ACEP, to participate in this forum. Your participation would be greatly appreciated by these physicians who are eager to remain active and involved in the development of sound health care policy.

We look forward to a favorable reply and can be flexible about the time of your presentation. Please contact Roslyne Schulman in the ACEP Washington Office at 202-728-0610 ext. 3014 for further information.

Sincerely,

John H. Scott
Director, Government Affairs

March 2, 1995

Memorandum to Anne McGuire

From: Marilyn Yager

CC: Jennifer Klein, Julie Demeo, & Julia Moffett

We should regret the request by the National Association of Health Underwriters to meet with the President. I would recommend a meeting with either Jennifer Klein or Chris Jennings, as we have done in recent months with most of the other groups requesting meetings on health care reform.

Regretted
3/2/95 KKD

NO as per Jen
3/8

Scheduling Advice Memorandum

FROM: BILLY WEBSTER FEB - 8 1995 DATE: 1/21

No Ack needed ____

TO:

JOAN BAGGETT	___	MACK MCLARTY	___
ERSKINE BOWLES	___	ABNER MIKVA	___
RAHM EMANUEL	___	LEON PANETTA	___
JOHN EMERSON	___	JOHN PODESTA	___
MARK GEARAN	___	~~JACK QUINN~~	___
JACK GIBBONS	___	CAROL RASCO	✓
PAT GRIFFIN	___	BOB RUBIN	___
MARCIA HALE	___	ELI SEGAL	___
KAREN HANCOX	___	PATTI SOLIS	___
ALEXIS HERMAN	___	GEORGE STEPHANOPOLOUS	___
NANCY HERNREICH	___	ANN STOCK	___
HAROLD ICKES	___	CHRISTINE VARNEY	___
WILL ITOH	___	MELANNE VERVEER	___
ANTHONY LAKE	___	DANNY WEXLER	___
BRUCE LINDSEY	___	MAGGIE WILLIAMS	___
AL MALDON	___	TONY WILSON	___
KATIE MCGINTY	___	Julia Moffett	✓

RE: National Association of Health Underwriters

The ~~Scheduling~~ Office is considering the attached invitation.
Please advise us:

X POTUS should/need not attend.

___ POTUS should/need not attend but should send a representative

↳ REFER TO MARILYN YAGER

___ If you think POTUS should attend please submit a scheduling proposal, **WITH THE INVITATION ATTACHED**, ASAP

Your Additional Comments:

PLEASE RETURN THIS MEMO TO ANNE MCGUIRE IN ROOM 185.5 BY 2/4

NATIONAL ASSOCIATION OF HEALTH UNDERWRITERS
PROTECTING THE INSURABLE FUTURE
NAHU

Office of the President

095273

December 9, 1994

The Honorable William J. Clinton
President of the United States
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mr. President:

I was sorry that we did not achieve health care reform legislation in the 103rd Congress. Many of us worked vigorously to offer all Americans universal coverage.

This goal remains as a high priority. NAHU's membership has over 13,000 agents, brokers consultants and other health and disability professionals who help over 40 percent of Americans with their health insurance needs.

Our hope is that you and the First Lady will work with us. I understand we may not agree on every issue, but there is more to agree on than not. The First Lady may have not understood what our value to the system is. Americans deserve the right to employ a health insurance advisor to assist with their selection if they so choose. Employee benefit group commissions paid to health advisors average 3 percent of paid premium. We too, feel health care costs must be affordable and available to every person.

In many ways our plan, REAL CHOICE, achieves the goals you set out. The outcome of the election does not alter our goal or our policy. It was not a compromise plan. We formulated a plan we could support in the 103rd and 104th Congress. I ask to meet with you so we may work with your Administration on a bi-partisan effort with Congress to achieve this most important quest. We would like nothing better than to deliver a message to the 120 million clients we serve that your Administration is working toward an equitable health care solution Americans can rely on.

I hope you will contact me or former representative Tom Downey who works with our Association. I wish you and the First Family a wonderful holiday season and a happy new year.

My warmest regards

Jay B. Grant, RHU

1000 Connecticut Avenue, N.W., Suite 810 ■ Washington, D.C. 20036
(202) 223-5533 *facsimile* (202) 785-2274

These remarks were edited to make the transition from speech to the written word. Some podium banter was deleted. Questions from the floor were often inaudible or unattributable. In such cases the response from the panelists were included when they contributed to the discussion given the absence of the question.

UNIVERSITY OF MINNESOTA

Twin Cities Campus | ***Center for Biomedical Ethics*** | *University Office Plaza*
Suite 110
2221 University Avenue S.E.
Minneapolis, MN 55414-3074
612-626-9756
Fax: 612-626-9786

April 17, 1995

Jennifer Klein
Special Asst to Pres for Domestic Policy
The White House
2nd Floor West Wing
Washington, DC 20500

Dear Ms. Klein,

Last May you participated in a conference, "The Role of Bioethics in Health Care Policy, Broadening the Bioethics Agenda?" sponsored by the Center for Biomedical Ethics, the Association of Academic Health Centers and the Greenwall Foundation. The conference was chaired by Steve Miles and Art Caplan. It was well attended and included a provocative discussion of the place of bioethics in health care reform. Audio tapes were made and are available for sale.

At the conclusion of the conference, many people expressed the desire for an Internet discussion of the types of issues raised by the conference. Since then, the Medical College of Wisconsin, Bioethics On-line Service, has become a widely recognized and used source of bioethics information. We are going to distribute the conference proceedings on this forum.

You gave a presentation at this conference, *What is Needed: Federal Perspectives.* You consented to have your remarks taped for distribution. We would like to review that consent with you as we consider the distribution of the conference proceedings on Internet.

Enclosed is a transcript of your remarks for the proceedings. Your remarks were edited to remove personal asides and answers to inaudible questions from the floor. Minor stylistic changes were made to effect a smoother translation from spoken to written material.

Please review the enclosed material and notify us if you have any objection or revision to this material. Responses may be sent to Center for Biomedical Ethics, 2221 University Avenue SE, Suite #110, Minneapolis, MN 55414-3074, miles001@maroon.tc.umn.edu, Fax (612) 626-9786.

Best regards,

Steve Miles/LH

Steven Miles, MD
Associate Professor,
Center for Biomedical Ethics,
University of Minnesota

Arthur Caplan/LH

Arthur Caplan, PhD
Trustee Professor and Director,
Center for Bioethics,
University of Pennsylvania

SM/lh

enclosure

Wikler: I'd like to ask the three panelists about the perception of what bioethics is and who bioethicists are and what they do. From within the profession -- if it's a profession -- we think of it not as a set of positions, but as a discipline or a subject to be studies. And then, people who work on the questions have number of positions often sharply contradictory to each other. And when we think about our peers and who we admire and who we don't, it's often on the basis how careful a scholar they are, how smart they are or whatever. Not so much whether or not we like their positions and we can admire people who hold positions that are very different from our own.

Sometimes in government circles I have the feeling that bioethics is seen as a set of positions on issues. For example, yesterday Zellman told us -- those of us who were here -- you people have been advocating universal coverage for 20 years. As if this position was the position of bioethics and our job was to come here and pressure for it somehow, like we were an advocacy group.

And Miss Klein, I think that when you said there was room for bioethics in Federal policy and you started laying out a set of (inaudible) in a health reform plan, you weren't talking about the need for deliberation of any kind; but, instead for the need for a certain set of standards of moral -- you know certain moral standards -- to be built into the features of a health care system. So it's more of the second kind of perception of bioethics that I was talking about.

So, when I was here with the President's commission staff, too, I often found that when we encountered Federal bureaucrats who had any idea of what we did. They thought -- they assumed that first of all that every bioethicist believed exactly the same thing. And that our job, if we had one, was to supply reasoning and principals that would underlie these positions that was something that they couldn't do.

So I'm wondering -- for all three panelists -- which of these two perceptions do you think is the one those people in the government who would not welcome bioethics have? And whether you think its -- whether it would be important for people in the field of bioethics to conform to this image however mistaken it is. Or instead, should we say, "That's not really us," and try to educate the Federal government about what we actually do and then insist they accept us for what we really are.

Klein: I think you are absolutely right that that's probably the perception, but I also think that you're absolutely right that that's not the role and that you should be clear about what it is that you do. I think in my experience the role of the bioethics task force and people I've met with subsequently has been to take issues which people generally, but especially people in Washington who are struggling to make a policy in a limited period of time want easy answers to and quick fixes to. And the talk show hosts want something to latch onto and say, "this plan is going to lead to rationing" or "this plan is going to lead to this," and I think that, in fact, the role of bioethicists in policy making is to elaborate -- to make clear that none of these issues are easy and that all of them by definition are complex. The role is to identify the complexities and, I mean, lay them out and discuss them in an intelligent fashion that a lot of people wouldn't even be comfortable initially thinking about.

Dubler: I certainly think that in Washington what people always want is a quick fix. It's not necessarily what you give them. But what you give them is also in question. And if the role of a bioethicist is to present the principles that could support an argument, it's too narrow a role in my sense. If we judge people by how careful, to quote you, "how careful a scholar they are and how smart," that's fine. But it should encompass more than just principles, having to do with empathetic reactions to problems and sympathetic reactions to problems and how elaborate the narrative is that can present the complex dimension of problems that don't get picked up. I would argue in a principled explanation.

So I think there are two things that need to be done. One is to say that's not what we do -- the quick fix. But what we do is very elaborated. And it isn't just a set of principles, it's a whole world of how people interact around medicine and health care. That's even a bigger task than I think you've proposed, but I think it's the one we have to struggle for.

Nishimi: I don't know that these individuals view bioethics as a monolith. I think they recognize that there are competing views, competing values. But them want some measure of articulation or synthesis of some of these competing interests. The rest of the world may well look at bioethics as a consensus and a value. And so then it is incumbent on everyone to educate these individuals and point out that isn't a body of knowledge. It's a process that can help shape their thinking just like there is a legal approach, just like there's an economic approach. And that it's a factor that they should weigh as policy decision makers.

Floor: One of the places it's come forward, I'd like to ask Ms. Klein what does she see as the role of a group like the Catholic Health Care Association working with the White House on health care reform.

Klein: I guess I think that CHA is probably a very different case than the academic ethicist or the individual offering their opinions. I mean, CHA has been a valuable source of information because of so much good that they do in health care today. And think they're appreciated for that reason. I'm not sure that their particular ethical principles are being adopted in any way. It's just another source of information for both the First Lady and the rest of the administration.

Wolf: I'm worried there are some problems lurking here that we need to surface that haven't yet. As we all know, bioethics is a multi-disciplinary, inter-disciplinary. With philosophers and every body else collaborating, when we started to go into the different forums (like the courtroom), we started to see bioethicists take a stand and play every role practically in the courtroom and suddenly we realized that we were in trouble. I'm very worried that we're courting that same analogous problem in policy sphere. I think that what bioethics is going to and what a sound ethical analysis may tell you may be awfully different from what an analysis of the legal implications are very different.. So I wonder how as we become much more active as players in the policy sphere, particularly on issues like health care reform where the bottom line is writing the statute. How we get a hold of keeping ethics and law separate enough so that we can discuss constructively how we should interact and where we should not.

Dubler: I think they are really distinguishable, Susan. I think you and I share the position that I think the idea of bioethicists going in to court to be a gun for hire for one side or the other. I, at least, think that is a truly terrible idea. And where it has happened, I think, it has largely done a disservice to the field. And the fact that it promotes a vision that we are guns for hire is I think in the long term is really not in the interest of the discussions. I think you can distinguish that, or at least we have to try to distinguish that, from the context in public policy. Which is, when we all got down to Washington the notion was that this was a secret enterprise. I don't understand exactly why that decision was made and I thought it was a bad decision then and I think it's a bad decision now. I think it alienated lots of people who didn't have to be alienated.

On the other hand, that was a given. That was the context in which you worked. But the notion that our arguments were as constrained as our physical ability to enter the OEOB was not the same. Or at least some of us argued it shouldn't be. This goes back to the issue that I raised. Do you go down or do what you're told to do or do you go down and try to set your independent agenda. I think many of us thought that what we should be doing is setting our independent agenda. That's very different from what goes on in court.

When you go into a court situation, you know what the interest of the client for whom you are working is. Unless you come down as an independent, fact finder for judge and even then I have some problems. But I think that's very different than mucking it up in the policy arena. Where what you're going to try to do is spot the issues and make your arguments.

John Fletcher, University of Virginia. Picking up on Dan's question about the recognition on the part of politicians, policy makers, or officials -- legal officials -- and disputives in controversies about what bioethicists do. It helps me to remember a distinction Ruth Macklin made between expertise about ethics and expertise in ethics. I think that there is a different role, because for expertise about ethics everyone of these issues has its own special history. And learning about that history and being able to tell it accurately and in a balance way takes a lot of work. To get the history of the issues clear and so decision makers, policy makers need to get educated about the history of the issues. That's one role.

The other is, I think, that policy makers have an intuition and they're right that ethics is about controversy, about competing ethical judgements. You are either going to have universal coverage or not. All right? You're going to either treat Baby K according to her mother's demands or not. And on either side rests -- either decision rests on a real ethical judgement. So, I don't see anything wrong Nancy, or others, for people in a dispute to invite persons in who have made a judgement and who can give the reasons in an open forum. They don't have to take money for it.

But my job is to -- in that forum -- is to give the best reasons for why the hospital could be in the right position with regard to a refusal of emergency treatment of Baby K. Fully expecting that somebody on the other side is going to give his expert or her expert reasons why the opposite judgement. I think that's perfectly fair

Male: My name is Dan Eisen although I am a physician and attorney in Madison, Wisconsin. As I said, I have been an expert witness in some medical cases. I have also been involved in public policy. I am a little bit confused by some of the talk that has been going on here today about the separation between what a lot of ethicists want to be on one level and the actual policy, and the actual events that are taking place on a day-to-day basis that to my mind are the things that really make a difference. There is a sense that if you get down into the politics or you get down into the courtroom, that somehow you are getting at a level that is maybe a little dirty, a little shameful. There is some negatives about it. But that is what makes people's lives different. We can sit up there and we can write things about great certain outlooks ought to be, and how different positions should be the way it goes, and we all have different opinions.

I have different opinions on issues such as whether or not people who treat themselves poorly by smoking should pay more for insurance than people who don't. But the point is that gets put into poll by going into policy. While in courtrooms law is made, and it is law that then has something to do with the fabric of lives, and ethics really has to be a part of that fabric. It has to get woven into that. And the only way it is going to get woven into our lives is by being there when those things that actually impact on our lives are created, whether than is an actual policy, an actual law or courtroom decision, whatever it might be. We got to be in there and we got to be in there fighting for our positions. And my position may be different than yours or yours, but -- and that is fine -- and you need to be there too. But the point is we have got to be there. We can't sit up there in our ivory towers and write these articles and then just expect the world to be a better place. Thanks.

Floor: I think a lot of us have agreed to disagree on the courtroom. It is -- there are good arguments on both sides. But I think the distinction between that and public policy forums is one at least that I think it a useful one to make. So whereas I take a position I think different from yours on the courtroom, I think the analogy between the courtroom and the public policy arena is, at least in my judgment, not a terrific one.

Female: That is interesting because I wanted to comment on this question of what I have called it a different setting, responsible, professional activism. One could argue that in bioethics some of the most important policy has been made in the courts. And if we want to follow up in our thinking about values with trying to influence outcomes in the policy world, that is one arena where it could happen. When Art Caplan says that we ought to be doing more about poverty in the Third World and foreign policy, and all of these important value questions, which I agree with him about, how are you going to do something about that without getting involved in this process that sometimes seems not as pure as our academic lives.

Floor: I think it is frustrating as someone who has begun to work on a little bit of this stuff when you try to further the -- further consciousness and policy on these questions in the role of bioethicists, because sometimes it feels like we really don't have that much to offer. But by placing it on the agenda and inviting others to get involved dialogue, maybe those who do have more to offer can be brought into it. And that is something that we can do without betraying -- or

cashing in on our status and pretending to be what we are not.

Floor: I think I am confused. And your supposition is getting me more confused. Presumably the people that got asked to go to the task force, however successful or unsuccessful it was, got asked for reasons of the physicians ethics expertise. Others of us didn't formally serve. We did other things and we are going to have to put that in our articles about the next policy. This Clinton health care reform process is not the last word. I don't really see it as this great distinction between you are in the policy process and when you are not . I mean, you are trying to do the best you can saying what you think needs to be and then getting it straight. The only way to get it straight is to go down and fight for your position. I don't really see what is wrong with that.

Floor: The fact that most of us don't get to serve on commissions and task forces. That there are other opportunities for input at the policy level than by testifying before various congressional committees, task forces, hearings, etcetera. About a year ago we created in Charleston what we called The Charleston Health Care Colloquium. That is a group of about 40 people throughout the Charleston area who are interested in the ethical policy, legal, etcetera, aspects of health care. They are drawn from our medical school faculty, from the faculty of a couple of local liberal arts colleges, from lawyers who work in town in the health law, from practicing physicians from in town. There are raspatory therapists. It is just a wide broadly based group. And we consider various issues from the pluralistic approach, including things like physician assisted suicide, invitro fertilization, embryo transfer, and the like. We are almost able to reach a surprisingly broad consensus on what this group thinks about those issues. I recently came to Washington to testify regarding the embryo research issue to the NIH panel. And testimony was enthusiastically received by the committee, by the panel, presumably we said what they wanted to hear and that they mostly had been hearing, is from right-wing, mostly the religious right, about how terrible embryo research is. And our conclusions were different from that and were much more supportive of what the panel ultimately is going to find. Probably because it is already decided what they are going to find.

And that leads to my question. Our colloquium would be interested doing a lot more of this, being as broadly based, pluralistic and presumably representative of community thought, than an individual bioethicist or group would be. How do we find out practically where such hearings are taking place? For example, the Baby K hearings that are coming up. We would love to testify about that if we knew that it was happening and when and where, etcetera. How do we find about those? And, secondly, how can we determine whether it is worth the price of an airplane ticket. Is anybody going to listen or care about what we are saying? How fixed are the conclusions that the panel is going to reach? And in what way, if any, can we learn about the various degrees of pre-made decisions that are driving these panels, so that we can pick the one that is worth going to and pick the ones that it is not worth going to.

Nishimi: I would be a very rich person and not sitting here if I knew the answers to the questions. Well, not to be flip, there's the widely circulated Federal Register that I know all of

you get each day. It is a difficult thing to know when certainly Congress is holding a hearing. It's difficult for me sometimes to know when Congress is holding a hearing and I work for them. Sometimes I'll get a call, "Oh, did you know they're having this hearing tomorrow?" No, you know, I didn't know. It is very hard to keep up. Sometimes it will be, "Did you know that we're having our hearing on Friday?" and this is a committee that I've worked with, you know, and had contact with maybe once or twice a week for months on end and all of a sudden they decide to hold a hearing at the last minute. So there really is no good way to always be informed.

Panelist: The Congressional Monitor is a publication which comes out everyday. There are always changes from what's in there but they supposedly list every hearing that at least Congress is holding. And so there are certain alert services to which one can subscribe. But again, these things change and so there will be things that you miss. In so far, as you know, finding out whether something wired or not wired and how influential your group's opinion may or may not be, I'd like to think that early on things aren't wired. I mean, there are always exceptions to that rule and I may be a little bit idealistic in that regard. But I think that most independent panels make a good faith effort certainly to be open as they move through their deliberative process. I think that's true both of executive branch panels and certainly some of the groups that I've worked with at OTA.

In a Congressional hearing, you are more likely to have, as Art indicated, some level of scripting or at least some level of invitations of people who subscribe to the Chairman's point of view. But there's always other members on the panel, you know, who want their witness, usually not as many as the chair gets. So they will listen. The other avenue is really through your own representatives and senators. I worked in a Congressional office for two and one half years and I could count on one hand the time that people who were in Washington, as many of you are from out of town. People came in and talked to me about matters that were important. Certainly in the biomedical and bioethics field. I got a lot of visits from the Texas Medical Association. I got a lot of visits from companies, but I didn't get a lot of visits from academicians and scholars, you know, trying to keep me informed about those issues that they felt were important and that they could contribute. It does sound kind of hokey but it does work at some level.

Male: Maybe that could be useful function for the AAB.

Floor: I'm Sharon Van Meter and I am a forensic pathologist in California and I really sympathize with the dilemma about advocacy versus intellectual honesty versus expert input. Because even though physicians are licensed, boarded, credentialed, and even wear a collar. There is no control of expert witnesses. And it is something that, of course, those of who do it a lot are very concerned about and there really hasn't developed over many, many years any mechanism to control them. And so I would certainly advise that, that type of control should come internally. I'm not how successful it will be. But there's always somebody who will testify to anything. Or will influence a policy for anything. So I think that keeping that within the control of the bioethics community, whatever that is, is certainly an important consideration. Because I do think that type of information if very important to be put forward on many of these

issues and to have some influence. I think the other thing that setting aside your world as an expert versus as an advocate is something else that I face in some respects and that is in a large metropolitan county I see hundreds of gunshot wounds every day. But what I testify to in court is how it happened and how many there are and what kind of bullets they were and that sort of thing. What I think about gun control or who did it is the time when I have to take off my own coat and face that issue differently.

Floor: I think it's a real danger from a consumer point of view to try to look at you and say, "What is it that you are offering? What is it that we are buying?" Are we buying a position on the issues or are we buying people who make sure that all of the questions are asked and all the issues are laid on the table. Which is it? How we answer that tells who we are.

Miles: It seems to me though it winds up being more complicated than that because sometimes you're invited to testify because of your position. Sometimes you're invited in as an example of a particular conclusion. Sometimes you're invited in to present and defend somebody else's conclusion, even though they really don't know yours. If they figure you're hungry you'll come and defend whatever position you're told to defend. Sometimes, for example, as happened with the rationing piece in the President's working group, I think that somebody else's position was that rationing would not be defined as an issue in this President's plan. And then there was a structured silence of the ethicists on the question of rationing and allocation which made it look like we unintentionally ratified that position. Very rarely are we brought in- to analyze the number of different positions. And the question of how we are fair in each of those four different types of roles and what is the possibilities of fairness and whether, perhaps, some of those roles should even be turned down. It really winds up being a very complex environment that we're invited into.

Floor: There been a lot of comments about distinguishing on the one hand sort of a scholarly role and on the other hand an activist role and the assumption that we need to get clear which we are. It certainly seems to me that it's not as if we have the choice of being one but not the other. Certainly there are contexts where we think of ourselves as playing more scholarly roles and so analyzing issues and analyzing arguments. Never the less, virtually all of us have positions. We think some arguments are better than others. And we have positions on the questions that we analyze. So I think too, to believe that we could take on one of those roles, particularly the scholarly role, without having some help with the elements of advocacy.

Battin: Advocacy as an organization is part of the purposes of the organization for the activities of the organization. You mentioned the AAB a while ago. Part of its actual constitution as an organization precludes the official taking of positions of advocacy on any matter within bioethics that might be under discussion, abortion, euthanasia, or any of those things. I think it doesn't, of course, prevent the members of that organization from taking advocacy on any question. I think that's an important distinction when you're thinking about the function of people in the bioethics orbit. I think that's a healthy step in this field to prevent that kind of thing.

I think there's another way to understand what's going on in bioethics and the issue of advocacy. As I see it, one way of painting a picture of the history of the development of bioethics is to see it as growing and flourishing at the rate it has partly because it is taking over from organized religion the role of commentator on matters of public morals. I think that is happening partly because organized religion, which used to speak in the days of ecumenicism with comparatively uniform -- and comparatively unanimous voice, has become increasing sectarian and dogmatic in recent years and has lost a great deal of credibility in. And as different religious organizations are now perceived to speak only for themselves. I see bioethics, or one way of seeing bioethics, is as rushing in to the void that has been created by the new derisiveness among religious groups in filling that role. The problem is that if that's the void that it's filling and this, of course, is one way of seeing bioethics. It tends to get cast in the same role that religion used to fill. That is as arbitrator of public morals and as the king of presence which doesn't need to give further reasons for the positions it takes. That's the point that is crucial. That bioethics properly conducted is an enterprise that gives publicly inspectable, rationally accessible reasons in a way that religion never used to have to do. That demand isn't kept up to the same degree. I think it's crucial to keep pressing bioethics in such a way to avoid allowing it to assume what is a very easy slot.

Miles: So in other words, all the problems of the church state relationship but none of the visibility. Is that what you're saying?

Floor: The problem that I see with this type of sound byte that we are so often invited to participate in is that I believe that the only kind of credibility and expertise and authority we should have is based on the quality of the arguments that we give. So what we do give the three second blurb we're really playing into a very different ball game.

Dubler: I think it's been a very interesting and rich discussion. I just want to end up with a playground metaphor which is, in the sand box of public policy, if you throw sand in the face of people who invited you in and steal their green pails and shovels, you're not getting invited back. And on the issue of whether you push ahead with rationing in a structure that has made a determined political judgement that it does not want to happen, you run the risk of not being invited back. Is that a risk you want to have? Do we really want to play in the political arena which political? If we do, there are certain constraints that you have to accept.

What is Needed: Federal Perspectives
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As I thought about what I wanted to share today, I was realizing that I had never really resolved the question myself about how relevant bioethics was to the Federal health reform debate. So, it was an interesting weekend for me. What I realized it that it is essential to the debate. Because when you start thinking about the question -- the fundamental question that's being asked now as the committees consider both the President's health care plan and other health care plans, is whether or not there will be universal coverage. Each of the proposals that are currently before Congress have been measured and continue to be measured against that standard. The problem is, once you get past that fundamental question is that the debate changes to the nitty, gritty politics of what an alliance is, whether there should be an alliance, what it should look like, how the system should be financed, whether through an individual mandate, an employer mandate, or some combination of the two. I feel, I fear that the commitment to bioethics is lost when you move beyond universal access to the questions of how to achieve it.

So I just wanted to raise the, sort of, three fundamental questions that I think need to have attention. Those three questions, beyond universal coverage, are. Do people have access to the services they need? Are appropriate services covered? Are these services of high quality?

The first issue to think about in answering those questions are whether services are truly available. The President's plan reinforces that we must eliminate pre-existing conditions exclusions, lifetime limits on coverage and the ability of insurance to charge higher prices because of health conditions. There has got to be an adequate choice of plans and health care providers in an area. And then finally, you have to assure that for all the plans in all areas, that there is real access to services. And in many cases, that means additional enabling services which need to be appropriated. For example, transportation, translation services. In addition to that, incentives for doctors and other health professional to practice in traditionally unserved areas.

The second issue is that the services must be appropriate. There is a lot of discussion going on now whether or not the benefits package should be specified in legislation. And I would argue that it should be specified in legislation and that it must be uniform and comprehensive. Starting with Uniform, today there is a confusing variety of insurance products on the market which, 1.) confuse consumers and 2.) allow insurance companies to pick -- what's called cherry picking -- on whether or not they are good health risks. Coverage must be comprehensive. A lot of the plans that are currently being considered have both a standard and a catastrophic package, or only a catastrophic package. I think that it's important to have a comprehensive to encourage people to get the health care before they get sick and to get the services they need when they need them. And, for many poor and low income people a catastrophic package is essentially no coverage at all because by the time they -- they're not able to spend up to the high deductible that is required.

Coverage should be specified in legislation rather than left up to a board or commission, because fundamentally if we're asking families and employers and the Federal government to pay, we have to know what it's going to cost and we can't leave it to a board which may later either come up with a very small -- a narrow package -- or a broad package. Within the benefit package there needs to be an appropriate range of services. And by that I mean both primary care and specialty services. The Clinton plan has gotten a lot of publicity for being -- for focusing on preventive care, for getting people into care before their illnesses or costly -- before they're serious. But, the part that gets less attention is that there also needs to be a focus on specialty services so that when those services are appropriate they are available. It is important to leave decisions about medical necessity and appropriateness to health professionals and patients in particular situations. Because only the particular doctor and patient in an instance is familiar with the details and the concerns in that instance.

This is a strange word, but I think that any health care system that gets enacted has to be acceptable to patients. And by that I mean that consumers have a role in the decision making. That means both in the choice of their health plan and in their doctor and in the individual decisions that they make about their care. That's why the Clinton plan includes quality measures that take into account consumer satisfaction. And that's why it includes significant grievance procedures. So that if there are disputes about, for example benefits, there is a mechanism to resolve those at the individual level.

And finally, it needs to be affordable because unless we get costs under control, universal coverage is a meaningless concept.