



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

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SESSION 1: FACILITATING PUBLIC DIALOGUE ABOUT BIOETHICS

DR. GUTMANN: And with that, we are going to continue this discussion in other ways with our, really, expert and wonderful presenters. I am going to ask the first panel of the day to come up to our table. We are going to focus on facilitating public dialogue about bioethics. And we will, as we have been talking about the intersection between deliberation and public ethics, welcome our first panel.

We will hear -- and I will introduce each of you in turn, as you speak, and then we will leave time for questions. We will hear first from Dennis Thompson, who is the Alfred Lord -- Alfred North -- I have given you -- Alfred North Lord Tennyson -- Alfred North Whitehead professor of political philosophy emeritus, professor of government and public policy at Harvard University, the founding director of the University-wide Safra Center for Ethics.

Dennis Thompson and I have co-authored a number of books about democratic deliberation: "Why Deliberative Democracy," "Democracy and Disagreement and the Spirit of Compromise: Why Governing Demands It and Campaigning Undermines It."

Dr. Thompson has served as a consultant to the Institutes of Medicine, the American Medical Association, the Food and Drug Administration, the U.S. Senate Ethics Committee, and the South African Parliament, among other institutions.

And I thank you -- we thank you -- for joining us this morning.

DR. THOMPSON: Thank you, Amy. And (speaking without microphone)-- in Miami, which was more pleasant than Washington.

(Laughter.)

DR. THOMPSON: So, the subject of deliberation. You have heard

already from the leading experts, you have read some of the best work. You have practiced deliberation very well. So at this point I am tempted to quote that great teacher of congressional ethics, Mo Udall, when he was asked by a new Member of Congress why the deliberation was going on so long in Congress. He said, "It is true that everything has been said, but not everyone has said it."

(Laughter.)

DR. THOMPSON: So, at least I will try not to say what I have already said in print, which some of you have read some of, or at least you better have read some of it, because Amy wrote some of it.

(Laughter.)

DR. THOMPSON: I will concentrate on just one part of my assignment, and I will try to answer the question of how we might be able to encourage more deliberation about bioethics now, not education, which I think Diana Hess spoke about very well at your last meeting, but now, without waiting for the next generation, which we hope will do it better among both citizens and leaders. And I will suggest that I think there is a category in between policy-makers and citizens, public leaders, opinion leaders, that we should be focusing on.

So, I will begin with a story. I will take a little bit of time to do that. It is a true story. I was involved with an attempt to demonstrate the need for deliberation about bioethics to a group in a continuing education program at an alumni event a few years ago. I will let you guess the institution.

The group consisted of about 20 high-powered professionals: lawyers, doctors, government officials, business executives, all leaders in their professions. Not necessarily policy-makers. The case we used was based on an actual incident in an

HMO affiliated with a Massachusetts -- I said I wasn't going to say -- hospital. And it was posing hard questions for different roles in the institution, for the lawyers, for the doctors, boards of trustees, and so on. And it featured a fully informed, completely competent elderly patient, cancer patient, in the HMO who asked his doctor for a prescription for a drug that the doctor knew would be used to commit suicide.

The hospital didn't have an official policy at the time to deal with such requests. Though, at least covertly, a number of the doctors would be willing to fulfill that, those kinds of requests. Most of the trustees, if asked, would say no. The law, the legal situation, was in flux at the time.

So, when we presented this case, in more detail than I have here, to this alumni group, several of them turned out to be really strongly opposed to physician-assisted suicide under any circumstances, private or public. And that was a surprise to some members of the group. So we had quite a disagreement. And those members of the group who had first thought this was an easy case suddenly said, "Well, no, it is hard." They tried to then avoid answering what should be done.

Several of the members of the group tried a common tactic, which you have seen, I am sure, in ethical discussions: "We need more information about this case. We need more studies. We need more" -- sorry.

(Laughter.)

DR. THOMPSON: Well, I had brought along one of my colleagues, who had been a physician in this very case, who happened to be Zeke Emanuel. This is before he became a target of Sarah Palin. Zeke was able, as you -- those of you who know him -- was able to give them all the information they could possibly want, which, of course, did not make the case any easier. We also brought out from behind the door,

when people started asking legal questions, a well-informed lawyer. So -- and we had a scientist. So, we had all the facts.

So one participant finally said, "Well, obviously, people of good will will disagree about this case. So each person should follow his own conscience, and do what is right." Everybody sort of nodded.

But then, an experienced CEO in the group said, "Do we really think that the hospital's policy should be that each doctor should decide on his own?" Everybody sort of stepped back. They now saw -- everybody saw -- that they had ignored something that, when they focused on the individual doctor and patient, letting each individual decide is not a solution to a problem of what the institution should do. The institution has to publicly defend and enforce the decision, whatever it is, even if it is doctor's discretion.

So, now, the participants saw they needed deliberation, not only to improve their own moral views, to become better informed -- which is what happened in a lot of the deliberative polls you have heard about -- but to try to reach a collective decision about the policy. And that means taking into account the views of other people in the institution, and the needs of the institution, as a whole, as full-blown, genuine deliberation requires.

So, this episode, I think, has some general implications that might be helpful to keep in mind, as you go about trying to improve public deliberation about bioethics. Let me mention four, maybe five, if I have time -- I will try to do this in a sketchy way.

First, to -- this addresses a question that you took up a few minutes ago -- deliberation is not just for citizens, but it is also for leaders. And that is a category in

between policy-makers and the general public. Many of the -- if not most, perhaps -- of the deliberative experiments and programs that you have talked about and heard about have targeted ordinary citizens, and you will hear more about that, and I think that is very important.

But it is not only citizens who need to learn how to deliberate. Leaders are not as good at it as they think. In fact, they may be worse, because they don't -- they think they have the answers. So that means that deliberative forms in educational programs should be designed to encourage leaders with other leaders and other citizens -- kind of hybrid groups.

And here, to go to your point, you don't have to create these from scratch. You can use existing institutions: professional associations; the bodies that run continuing medical education; the various conferences, retreats, workshops organized by institutions like the Aspen Institute; hundreds of advisory groups; private sector; non-profits dedicated to improving government, like the Congressional Management Foundation-- they maybe haven't done that-- but they actually organized a deliberative interaction online with constituents and 12 Members of Congress on some controversial subjects. So leaders.

Second, deliberation needs facts, but it doesn't end with facts. The issues are too important to be left for scientific experts. You heard some testimony about that in the previous meeting.

Now, at the May meeting, Steve Joffe made a cogent case for the need for more empirical research in bioethics. I completely agree: you can't deliberate well without being informed about the facts, about the relevant science. But as my example showed, especially when you get leaders and experts, they try to turn ethical questions

into factual ones. And they don't immediately see that there is much room for systematic reasoning about moral questions, as much room as there is for factual ones. So part of our job is to try to persuade people, yes, facts, science, but that is not the end of the story.

Third, deliberation, even with people you disagree with, can be fun. Well, if not exactly fun, then at least satisfying. In our alumni group, we were -- they were surprised to find they disagreed. But -- it was a little uncomfortable at first -- but once they got over that and later they said, "This was very important and we benefitted from it."

So -- and that is not just true for this highly-educated group. There -- some very recent research shows that ordinary citizens in deliberative settings have similar reactions. A study of a deliberative forum on health care in California found -- I quote -- "Participants experienced higher satisfaction with deliberation when there was moderate ideological difference in the group than when there was either polarized opinion," which -- "or more to the point, when there was homogenous opinion," and agreement. That runs counter to some of the earlier studies you have heard about.

And this is an excellent study. It has to be, because the authors make a point of saying that their conclusion supports Gutmann and Thompson against their critics. So there.

Fourth, deliberation can be propagated. Because it is only effective in relatively small groups, the impact -- at least some critics say -- is bound also to be quite limited. But in our case, we learned that they went -- our participants went back, talked to other -- they were opinion leaders. They went back and talked to other people

generally, spread the deliberative gospel.

And that is not unique to this special group. There is another also recent study in the Journal of Political Communication that found that citizens who participate in deliberative actions, if they are well designed, were more likely to continue to talk about the issues, to engage with neighbors and coworkers in ways that they did not before. And this was a kind of equal opportunity. There wasn't a bias in favor of class or education.

We can create multiplier effects in other ways, I think, by organizing conferences, publications, publicizing the successes of deliberative projects. In bioethics alone there are dozens, if not hundreds, of efforts underway in this country in a broad -- and I found, as I go around, many of the participants and many of the leaders are not even aware of the things that are going on elsewhere, even in this country, which suggests that bringing the leaders of these efforts together on a regular basis would be a useful thing to do, and to recommend, and to organize.

I have a couple of more suggestions, but let me just move quickly to my last point. Technology now makes possible not only online deliberation, an admirable example of which was Margaret Little described at your May meeting, but online instruction about deliberation. So I would suggest videos showing best practices and perhaps some worst practices could be developed and made widely available.

The Commission could start by identifying some of your best moments of deliberation, not only the successes and the results that Amy talked about earlier, but show us how you did it, little snippets. Now, you will need a professional videographer to do a little editing and some commentary, but why not? And there are other -- the Nuffield -- there are other commissions and there are other examples. And we don't

have that. We don't have enough of that.

What about the bad moments? We have to look elsewhere -- not here, certainly. And I suggest perhaps the greatest deliberative body in the world, the United States Congress. Thank you.

DR. GUTMANN: Thank you. We will take questions and comments after we hear from all of our presenters. And next we welcome Sir Roland Jackson, executive chair of Sciencewise, the UK government program I mentioned this morning that encourages and supports the use of deliberative public engagement to inform policy and decision-making on issues involving science and technology.

Sir Roland is also a member of the Nuffield Council on Bioethics, and served on the working group -- the working party, as it is called there -- that produced its latest report entitled, "Children and Clinical Research: Ethical Issues."

Welcome. We are really pleased to have you.

SIR ROLAND: Well, thank you very much indeed. And thank you very much for inviting me. It is a real privilege to come here. It is a real privilege to be able to come here, both on behalf of Sciencewise, and as a member of an equivalent body -- a rather different body, but an equivalent body across the pond, and to hear everybody else speak today.

So I have been asked to talk about three things: the reasons for engaging the public, by which I mean the broader public, in debates about ethical implications and advances in science and technology; effective methods of public engagement to that end; and the ways that public dialogue can get integrated into developmental policy in this area, and all the things that you raised in your opening remarks. So, reasons for public engagement, methods, and policy integration.

So, to start with the reasons, I will just list six very briefly, which may stimulate some discussion later.

The first and, in many ways, I think the most important, is to hear the often unheard voices, by which I mean that often silent majority of people beyond the organized and vociferous stakeholder groups. Because too often, and again that was hinted at earlier here, important issues are dominated by lobby groups, pressure groups of all sorts of shapes and sizes, and I think it is important to hear the voice of the reasoned majority behind those groups.

Second is to reflect societal diversity. That links to the first point. I think it is critical not just that unheard voices -- the often unheard voices -- are heard, but that those voices that are heard genuinely do reflect appropriate diversity and balance across society. That is not easy to do, and we can maybe talk about some of the issues around that. But I think that is really important.

The third reason is to challenge expert framing and assumptions. We certainly have a whole range of experience in the public dialogues we support, which indicates that lay people -- people who don't have that deep expertise based in science or law or whatever -- can and often do ask questions the experts hadn't thought of, or at least ask a question from left field, often based on an approach in values that makes an expert suddenly sit up and listen. It is remarkable how often in our public dialogues experts report the public helped them see the wood from the trees.

The fourth reason, which may seem a bit strange given the fairly small numbers involved, which was, I think, hinted at earlier, is to increase democratic legitimacy, even with those small numbers of people involved in deliberative dialogues. And I think the reason for that is that we know, certainly in the UK, that quite a lot of

people would like to be involved, or have the potential to influence public discourse around issues in science and technology. But even if they don't want to be involved directly -- and not all do -- most want to know that it is possible that some people are doing that, some normal people are involved in that process. And I think, if one can do that and convey that, that increases the legitimacy of what comes out, in terms of policy.

The fifth is to give decision-makers the confidence to proceed. I think your highlighting earlier the mitochondrial replacement is a real case in point. This is especially important in heavily contested areas, where public acceptability and value clashes and so on may be a major concern.

So, in the UK, that discussion that preceded our parliamentary votes on mitochondrial replacement was actually quite critical in giving policy-makers both the evidence and the sort of sense that there was enough will and support within society at large to support this under strictly regulated conditions. I was interested that one of those conditions was it should be only for the treatment of disease. There were a number of quite interesting caveats put out by the public.

And the sixth, and final reason for public engagement, deliberative public engagement, is to help frame communications around whatever policies are being discussed and decided. There is actually quite a narrow line here between legitimating already-decided policy in order to sell it -- which I think is not appropriate, maybe appropriate for a policy-maker, but not for deliberative dialogue -- but I think it is appropriate and useful to use deliberative dialogue to help shape the way in which people would like to be communicated with, and how they would like engagement to continue as a policy is developed and implemented.

And, actually, that is quite a common reason for government departments

coming to us, wanting to commission deliberative dialogue. For example, around fracking for shale gas is a recent example in the UK: pretty sensitive.

So those are six reasons for public engagement. What about the effective methods? Well, in a broader sense, they obviously depend entirely on the purpose of the public engagement. For example, whether you are engaging primarily to tell people something, to listen to them, or to shape something together. And I am going to concentrate on the approach of Sciencewise, which is actually matched by the Nuffield Council on Bioethics on the occasions when it has used the same methodologies.

And, as Dr. Gutmann has just explained, Sciencewise is a -- it is a UK government program funded by a government department, the Department for Business Innovation and Skills, which aims to improve public policy-making involving science and technology by increasing the effectiveness with which public dialogue is used in that process.

That, of course, means that the issues raised and discussed go well beyond the bioethical, but those are often there, too. But ethical questions, in general -- for example, around equity, around power and control, around regulation, around tradeoffs -- commonly surface in public dialogues on a whole range of topics, including around emerging technologies and biotechnology. So I think there is a lot of commonality between what we do and a specific focus on bioethics.

And I think it is important to note that, for us -- and by "us," I mean Sciencewise -- to support a public dialogue, there has to be a policy decision capable in principle of influence. I mean, even if it doesn't influence, there has to be something, in principle, capable of influence. That is the purpose of the engagement.

And if we think that we are being offered something that is purely for

legitimation, sort of cover for a decision that has already been made, then we will challenge that, and we may ultimately not support it. It can be quite difficult to work out whether that is happening. But with sufficient challenge, one can usually find out.

And the methods we use are those of facilitated, deliberative dialogue, with diverse, small groups of people recruited to be representative broadly of society, as a whole. The process often involves groups reconvened and meeting over a week or more, and typically then also talking with wider people, you know, with communities and friends. So it does spread out beyond that small group.

And crucially, as well, it is overseen by a stakeholder group, which incorporates the various different interests in play. And that oversight group is really important, because it helps ensure that the framing of the dialogue carries wide support, the materials and presentation are balanced. And, of course, it also helps with later buy-in to the outcomes. If you have all the warring factions, if you like, if you can get them in the same room to agree the process, then what comes out is likely to carry more weight.

And only once so far have we had an oversight group collapse, and the process fail. So it does happen, but for the most part we have managed not to result in that outcome.

And I think, especially in relation to the way that bioethics bodies tend to operate, it is important to note that we don't aim for consensus. These are not citizens' juries, they are not consensus conferences. The richness of what comes back from deliberative dialogue is plural and conditional, plural and conditional responses. It is then up to the policy-makers, the decision-makers, to interpret that and to draw their own conclusions.

It is also not opinion polling, and it is not quantitative. And whereas opinion polls tell you what people think, or what they say they think at a particular time, they don't really tell you how people think about the issue, what they might trade off against, what else they want to know, or how they might respond when challenged or presented with something different. I think deliberative dialogue gets under the skin of people's thinking, and picking up some points earlier, under the skin of experts' thinking, as much as it does of that -- of lay people. It is often complemented by opinion polling, but it gives different and, I think, deeper and richer information.

So, finally, ways that public dialogue can be integrated into policy development. Well, I mean, to be honest, all that is required is a bit of political will, and the commitment of policy-makers, and that, of course, sounds easy.

[PA INTERRUPTION]

SIR ROLAND: Government or politicians are inevitably ideologically driven. That is why they are there. And deliberative dialogue can be rather challenging to ideologies.

And, from a practical point of view, policy-makers and advisors are busy people. Their time scales for decision-making are often much shorter than for proper deliberative dialogue. And expense can be seen as a challenge; deliberative dialogue is not cheap. Although we do like to say that if you think dialogue is expensive, try conflict – [INAUDIBLE]

We can actually point to examples where dialogue saves substantial sums of money that can be quantified. And there must surely be many examples where a conflict foregone has saved money, quite apart from leading to better outcomes. But again, picking up points just made, demonstrating those impacts, and especially

establishing cause and effect, is inevitably very difficult for a whole host of reasons.

We, like you, I think, have an extensive tracking process to help us identify impacts as far as possible, but it is a real challenge.

So, in terms of integration, I think what is needed, apart from political will, or at least political support and license, is a cadre of policy-makers and advisors who are familiar with the potential for public dialogue, along with all the other tools of what we now call in the UK "open policy-making." And that means clarity about when not to use these techniques, as much as when to do so.

We, therefore, put quite an emphasis in the UK on capacity-building, as well as into direct support for the dialogues themselves. So we will run workshops in government departments, we will support official civil service training programs, and offer mentoring, and so on.

We find it really important for integration that policy-makers themselves commission the dialogues. They have to have ownership. So at Sciencewise we support and we often co-fund the dialogues, and we support their evaluation, but we do not run the dialogues ourselves. They have to be owned by the people who are going to be potentially influenced.

And we found that direct or past experience of public dialogue by those commissioning them is also important, not least for establishing their validity. It is very common for experts, once directly exposed and involved, to comment on how sensible and useful those public views are. And you get that by direct experience; if you just tell people it doesn't quite work the same.

But even so, the question of validity, of what comes out, of what actually counts as reliable evidence, is an issue that often arises with us. I think qualitative

methodologies like this are still seen as suspect, particularly, dare I say it, from some from a natural science or economics background. And to help meet that challenge, we have been working in the UK to develop a quality framework for public dialogue as part of a quality assurance process. And I would be interested to exchange, offline, some experience on that. I see you are clearly struggling with the same issues.

I will just end by noting that the Nuffield Council on Bioethics has itself used deliberative dialogue to inform some of its own reports, by which I mean deliberative dialogue using recruited public groups. For example, the report on dementia, ethical issues, and the reports on human body donation for medicine and research both used that process. And, in fact, the whole approach to our recent report on children in clinical research was one of participatory public involvement alongside the expert analysis. And I expect that use to grow in Nuffield reports.

So, thank you very much, again, for inviting me. I am much looking forward to hearing from everybody else, and to any discussion that might ensue. Thank you.

DR. GUTMANN: Thank you. Thank you very much. We will now hear from Marion Danis, head of the section on ethics and health policy in the Department of Bioethics in the Clinical Center of the National Institutes of Health, and chief of the Bioethics Consultation Service at the NIH Clinical Center.

Dr. Danis served as president of the International Society on Priorities in health care from 2008 to 2010, and on the board of the American Society for Bioethics and Humanities from 2008 to 2010. She has published many articles on patient preferences, and to the extent to which they are incorporated into practice.

We look forward to your comments. Welcome.

DR. DANIS: Thank you very much. It is a treat to be here. And I have been asked to talk about the work I have done with colleagues Susan Gould and people at the Center for Health Communications Research at the University of Michigan over the last decade-and-a-half in involving the public in priority-setting decisions through the use of the CHAT exercise.

I just need to say that I am expressing my own views, and not the views of the NIH.

So the CHAT exercise is really designed to help get the public's input on tough questions that come up when you don't have enough money to do what you want to do and meet all the needs you hope to accomplish.

We think of this as accomplishing or contributing several benefits. As others have said, it can promote democratic legitimacy, and it is important -- besides the fact that we have other approaches to getting public input -- that it be, in some ways, more effective than other mechanisms of representative democracy, and we think that, because people are not simply voting, just giving a yes/no answer -- they have to give reasons and they have to deliberate with each other -- we get more informed and carefully thought-out choices. It ensures that priorities reflect the values and preferences of the public, and it really means that, ultimately, if these views are taken into account, the needs of the population being served are likely to be better met.

The process can also increase the likelihood the priorities will be acceptable to the public. We often hear the public feeling like someone else has imposed priorities on them, and the limits are simply somebody else's ill-conceived ideas. But to the extent that they are involved themselves in making these tough choices, they appreciate that -- the decisions that are made.

And I think, in the process, this sort of deliberation enhances the public's understanding of the need to set priorities. It allows also for less partisan discussion of pressing needs. As people have said before, these kind of issues are so often fraught with irreconcilable loud voices, and a deliberative process like this can really overcome that kind of tenor of the conversation.

So let me turn to describing the features of the CHAT exercise. It is a structured, small-group exercise, in which about a dozen people participate. In any one project in which we use the exercise, hundreds of people can participate in such groups. We use a game board that represents the benefit options for people to pick from. And we give people a set of markers that can be stickers, they can be pegs, they can be -- when we use a computerized version, they can be markers moved electronically. And participants go through four rounds of decision-making specifically designed to give them skills in doing the choosing and in negotiating with each other.

So the first round usually involves an individual deciding for themselves what their priorities would be if they were interested in -- from their perspective. The second round involves triads of individuals in this dozen or so group who are assigned the task of making decisions for their community. In the third round, the entire group of a dozen people will participate in actively making a decision for their state or for their national government. And in the fourth round, they make decisions again for themselves, and we can compare the decisions at the beginning and the end to see how the deliberative process actually influences their thinking.

We use a number of materials to facilitate the ease of public understanding of these complex issues. We use health events, cards that have stories on them, so that between rounds they see examples of the impact of the decisions they would make, and

they discuss them. We use very easily-readable manuals for them to see what the benefits are. And I just want to say that we have got -- the manuals are made to be very inviting, easily understood, and salient. They bring the various options to the table for them to understand in language at their -- at a sixth to eighth-grade reading level. And we also have a facilitator script.

There is a lot of preparation for a CHAT exercise. Those who are planning an exercise have to clarify what the policy question is. They have to identify the candidate benefits that they think are relevant for the public to consider. And not just relevant, but prudent and worthwhile options, rather than a whole range of options that might not be very appropriate. They need to consider what is the reasonable expenditure for people to have at their discretion for using.

And, in general, the ratio between the cost of the basket of benefits and the pot of money they have is about 1.3 to 2. So the degree of constraint, we think, is manageable.

And then, we also, obviously, have to think about who is going to participate, and what is the relevant population, and how do we get the relevant population at the table in a way that is going to give some reasonable representation.

We have designed several versions of the CHAT exercise, and I just want to mention those. CHAT, which stands for Choosing Health Plans All Together, has been used to prioritize health insurance benefits for health insurance plans. The REACH exercise -- which stands for Reaching Economic Alternatives that Contribute to Health -- is meant to allow the public to participate in thinking about how we address health disparities, recognizing that there are a number of factors aside from health care that contribute to the social determinants of health. And there is Choosing Health All

Together, which prioritizes patient-centered outcomes research for PCORI. And, in general, we have a computer-based version that can be tailored to any exercise.

We have covered a number of policy questions with regard to health insurance, including coverage for the uninsured, Medicare population, Medi-Cal, populations who are disabled, micro-insurance in rural villages in India, and services for people who don't have insurance at all.

This is an illustration of the CHAT board. And you can see that it is a round circle with the benefits represented in pie-shaped images on the board. And each of those pie shapes has a number of dots on it that are a function of the actuarial cost, so that people are making choices based both on the expected benefit and cost.

These are some of the benefits that were laid on the table for the REACH exercise, and they fall into several policy sectors, including health, education, employment, nutrition, housing, neighborhood, et cetera.

This is the REACH board, and you can see that each of the policy sectors is represented by a different color. And here is an illustration of people participating and using the REACH exercise. This is an image of them in the second round, where they are working in triads to make their choices, putting stickers on their CHAT board. And here is an image of the facilitator working in the group round. We audio-taped this, so that we can then analyze the reasons. And the facilitator puts markers on this big board that is at the front of the room.

What are some results? We generally can collect quantitative results, including socio-demographic characteristics of participants, the initial and final choices, the group priorities, the attitudes pre and post exercise, to see if there are (sic) any change in attitudes, and qualitative results to understand the reasoning involved in the

public's deliberation.

Just to summarize, we have had experience with over 5,000 participants, asking questions in -- related to research, policy, and teaching. We have also had international users in New Zealand, Switzerland, in the UK, and in rural, low-income communities in India.

Some key findings from our work, in general, are that participants find the process very easy to understand, informative, and enjoyable. And the choices during the group rounds tend to be more community-minded than the individual choices. Individuals repeatedly, in one project after a number (sic), tend to be willing to abide by the group choices at about 85 percent.

And participants become more willing to accept resource constraints. They recognize, more so at the end than at the beginning, that there is a need to limit expenditures. And participants become more practiced in making tradeoffs.

We see that there is an evolution of individual priorities. For example, in the REACH exercise we saw that people became more interested in daycare for working parents, counseling for people with mental illness, and health behavior interventions, all things that experts would argue are useful.

We can also look at the association of demographic characteristics with individual priorities, because we have got a large sample, and we can do multivariate analysis. So, for example, in the REACH exercise we saw that Latinos were more interested in services related to adult education and daycare, and African Americans were more concerned about having food stamps and income supplements.

What is the impact of CHAT on policy? I have to say we only have few examples. And I will just mention that one was a project in Galveston, Texas, where

the public low-income employees were offered an opportunity to have a community-based, community-funded insurance -- not insurance, but health services in the absence of insurance. We have also seen that in the Medicare or the Medi-Cal CHAT project, feedback was given to the Department of Health Care Services. And in a project done in California, also in the Capital Region CHAT project, employers had their employees involved, and feedback was given to the employers, when they were trying to decide what their coverage would be for their employees.

There are, of course, some limitations. It is a resource-intensive process. But I would argue that if you compare it to the cost of things like running elections, you look at conflicts that don't get resolved, it really may be well worth it.

There are certainly questions about how to deal with the fact that you are not getting a random sample that is representative, and we tried to deal with this by collecting information so that we can determine the interests of people who come from different characteristics. And there is, I think, from our perspective, a real need to still work on translating findings into policy.

So, in conclusion, I would say that, from our experience, structured public deliberation regarding complex and contested priorities is possible. The process can improve public understanding, and fosters meaningful dialogue on a contentious issue about setting priorities, and yields information about the public's preferences. Such deliberation, I think, though, remains to be used better than it is. And there is a website, for those who are interested in the online version. Thank you.

DR. GUTMANN: Thank you. And we will all check usechat.org. Thank you very much.

We will close this session of presentations before we open it up for

questions and dialogue with our final speaker, Florence Evans. Mrs. Evans participated in the public deliberation "What's Next, California," which took place from June 24 to 26, 2011, in Torrance, California. She is a retired teacher who has been married for 49 years, is a mother of 4, and a grandmother of 1, all of which I relate to very strongly. And I welcome Florence Evans. We look forward to your comments.

MRS. EVANS: Thank you so much. This is quite an impressive group of people to be with. I represent the normal, average person who participated in a deliberative poll. And I think the way that I can share with you about it is just to take you through what I experienced, and then some of the realizations that occurred to me after -- that still are occurring to me.

This was four years ago that I participated in this. And it started with a phone call around dinner time. And you know those dinnertime phone calls, you don't usually want to answer the phone. But this lady called and she said, "You have been scientifically selected" --

(Laughter.)

MRS. EVANS: -- "to participate in this deliberative poll," and I am -- my brakes are going on, and I am thinking, okay, what does she want? Who does she represent? How much money is this going to cost? And then, I said, "How did you get my name?"

And she said, "You have been scientifically selected."

(Laughter.)

MRS. EVANS: I wasn't going to get her off that answer. That was the answer, so I didn't ask any more. The further she explained, I -- when she said it was going to be moderated by Judy Woodruff from -- I can't think -- yes. And then they

were going to make a documentary for MacNeil/Lehrer News Hour. I thought, okay, I recognize those names. So it is okay, I can do this.

And it sounded very interesting to me, but, of course, it was an unknown activity. And so, what happened after that invitation and agreement to come was I received in the mail about an inch-thick sheaf of papers. They were stapled together, and they were what we were going to be discussing.

And so, let me set the scene a little bit. June 2011, when this happened, was right at the beginning of Jerry Brown's governorship of California for the second time. And the -- and Arnold Schwarzenegger had just finished. And there were a lot of problems in our state, a lot of problems. And so everybody was talking about it, you know. Every -- people like myself, normal.

And so, we were interested in how they were going to discuss these things. And the 100-page booklet mailed out to us to read before we arrived, the focus of our deliberation was four parts of government: the initiative process -- which is how the citizenry can make some changes in the laws and policies of the State of California; the legislative structure -- should it be part-time or full-time legislation? ; third section was government: state and local -- which items should be for the state to decide and which ones for the local to decide; and the fourth one, taxation -- how are you going to pay for all this?

So, that was helpful, to get that booklet, because it gave a foundation to what we were going to be doing. And it took away some of the mystery. I read my book, so I could be prepared. And so each section in the booklet was followed by a list of proposals for addressing that topic, with pros and cons for each proposal. And it was simply written, and easy to understand, had graph charts, a glossary, and all kinds of

things.

We were given a survey on the phone before we left our house. We were given that same survey when we got there on Friday. This ran from Friday afternoon until Sunday afternoon. So we were given this survey three times: on the phone before we got there, when we arrived, and Sunday before we left. The Sunday before we left, the survey included evaluative questions to help them -- the people that were running this -- know how they were affecting the participants, and if their goals were met.

When we got to -- oh, first, they paid for everything, just like now, thank you very much. I flew from California yesterday, all day.

So we were put in small groups with a moderator. Our group was about 12 people in size. It was more people than are sitting right here, and it was a long, narrow table. And you had to sit in the same place each time, because they were filming it with little, small cameras that were unobtrusive, because they were small. And the moderator sat at one end, one narrow end of the long table. And her job -- I thought they were grad students, I think -- her job was to keep us on track, so that we wouldn't go off on wild tangents and waste time.

We were not to come up with a group consensus. We weren't. We were simply to consider the pros and the cons, which I found really helpful, because I had not thought of some of the things that were presented to us to think about. So it was an education for me.

As a group, we were to come up with one or two questions that our moderator wrote down on a card and gave to Judy Woodruff, and we had a plenary session. I may be saying that wrong -- I don't know if it is plenary or -- plenary? Okay.

At the end of each part of the day were -- there were 25 groups doing

this -- we all met in a big ballroom. And Judy had all the questions that people -- each of the 25 groups had asked, and there was a panel up on the stage of -- and there were different people each of the 4 times that we gathered.

There were political -- you know, congressmen and city councilmen from LA and professors from schools, and people from think tanks. The think tanks that I remembered were California Forward and California Common Cause, and there were others. They were all listed at the back of that book. I was going to bring the book, but you know, after four years, I don't know where I put it.

(Laughter.)

MRS. EVANS: So -- but what I am able to refer to as I speak to you is that -- and I am kind of jumping a bit -- but at the end we were encouraged to find a way to become involved in the process of governing California. Not necessarily running for office, but just to be an active citizen.

And so, one day I saw Paul Hurley. He was the editor of our newspaper. I live in a small town, 129,000 people. And it is the biggest town between Bakersfield and Fresno, all agriculture out there, in the midst of a drought. Anyway, saw Paul and I told him what I had just experienced, and he said, "Would you write an article?" So I wrote an article, and he printed it in the newspaper, and that is what I am looking at. And I did send it to Lizzie. I also emailed a copy of this to Jim Fishkin, whom you did meet last May. And so that is the only reason I think -- that is the only thing I did that might be the reason I am sitting here, I don't know.

(Laughter.)

MRS. EVANS: Anyway, they -- the people who put this together wanted 300 participants, so they invited 400. All 400 came. And I -- so they had to scramble

for more rooms and more food and what to do with these people. And I saw Mr. Fishkin at a break during this event, and I said, "You know, I think maybe the reason all 400 came is because it was indicative of the frustration that most all Californians felt. We thought, 'Yay, we have a chance to say something to maybe make some difference.'" He, also being a Californian, agreed.

There were -- oh, I put there were 19 people in my group, not just a dozen. And it was -- I am going to read a little bit, because I am sure -- "It was an amazing experience. We were a bunch of strangers from all different backgrounds, economic levels, political persuasions, ages, ethnicities, and professions, and we were all respectful of each other." That is the part I really, really appreciated.

I mentioned I am a retired teacher, and the last 12 years of my teaching I taught literacy, English as a second language, to people who didn't speak any English. If you spoke no English, you came to my class. So we did a lot of laughing. But, you know, just to break the ice and let them not be afraid of me.

And everybody was respected, I really liked that. The young man sitting to my right, he looked like he might have -- he was dressed like he could have been a street person, and had some tattoos and stuff, not somebody I normally run into in my daily life. But he had good things to say. And it was a great experience. The lady to my left was from my demographic, gray hair and older and grandmother and all that. And we were all different, from all over -- California is a really big state, so we had a lot of territory covered.

So, everybody was respectful of each other, listening to one another, expressing different thoughts, observations, considerations, and concerns. Everyone spoke up at least a few times. And I thought that was the norm for all the 25 groups,

until later in the -- I need the water, too much talking -- later in the experience, the young man to my right, he said not everybody had the same experience that we were having. Some of them had people who dominated the conversation, so not everybody could speak. Some had angry people that just, you know, destroyed the tone of the whole session for us. But we didn't have that, thanks be to God. Everybody was respectful.

And there were a couple of times some responses to some of the comments -- topics we had to discuss, some were highly charged, and said with emotion and -- if there is too much emotion, you can't really think, you know, and respond. So we got through that. It didn't dominate it, it didn't destroy the collaborative spirit.

Okay. So, now -- let me get this drink. Our moderator told us that, in fact, Mr. Fishkin's son, who had been an observer in the room, typing on his laptop the whole time, he told his father, "You have got to come look at group four, they are doing it just like you said."

(Laughter.)

MRS. EVANS: That explained why the head man, Mr. Fishkin, had come in during our discussion of taxation. Some other people who had been relatively quiet during the first three discussions spoke up quite a bit during this last part. We had been told there would be observers coming in and out, that we were not to interact with them, and to ignore the cameras as best we could. It wasn't hard, because the cameras, as I mentioned, were small and unobtrusive, and the conversation and exchange of ideas in our group engaged us and held our attention.

So, everybody was involved, at least by body language and expression, if not verbally. And it was eye-opening and encouraging to me to see that we could

discuss the workings of government from our varied perspectives, and do so civilly.

Civilly is a key word.

It also illustrated that average, everyday people had legitimate contributions to make in regard to our state, and that they would do so, if given information and opportunity. I think that is really important, the really important part: that average people whose daily lives don't get them involved in decision-making like is happening here, they are just doing their jobs, raising their families, living their lives, and -- but they do have opinions, very strong opinions about the things they see in the paper or hear on the news. And so, if they are given information and opportunity, they can contribute to the well-being of all of us.

And so, that is my story. And if you have any questions, that is it.

DR. GUTMANN: Thank you, all four participants, very, very much. We are open for questions and comments.

I am going to begin -- I just want to underline a few things that -- I will begin with Florence. I just want to punctuate something you said, and draw a important point from it for our recommendations and our discussion. You said all were respectful of each other, "and that is the part I really, really appreciated." You said --

MRS. EVANS: I did.

DR. GUTMANN: I am quoting you exactly. It is very important -- Dan pointed this out at our last session -- to recognize that deliberation is not simply a process, it has substantive values embedded in it. And mutual respect is, first and foremost, the substantive value. And that value has to be taken into account when one assesses the use of deliberation, compared to alternatives. Regardless of the outcome of deliberation, it instantiates, embeds, the value of mutual respect, which -- the

alternatives that are -- existing alternatives don't.

And people really -- you are not unique in this regard -- people, both ordinary people and, you know, extraordinary people, who -- public leaders, as Dennis said, who, when they interact and they don't have exclusive authority, they really, really value getting the respect of others, even -- or especially -- when people disagree.

So that is a value we have to, as an ethics commission, a bioethics commission, we have to defend that value, because people really, really appreciate it. So I just wanted to make that point, from the get-go.

MRS. EVANS: I think if you don't have that respect, you can't go forward.

DR. GUTMANN: Well, that is what we -- and that is the consequentialist part of it. I wanted to begin by saying that is a value, in itself, because people value it. It is not a peculiar value.

MRS. EVANS: No.

DR. GUTMANN: But there is also a consequence to that value, because, if you don't practice that value, you get the gridlock -- name-calling, character assassination -- all go together with not moving forward, especially in a polarized environment, but not only in that.

So, I think that is just a very important point for us, as a bioethics commission, to make about -- so many of the issues we deal with are very controversial issues. They wouldn't -- we wouldn't be deliberating about them if everybody agreed on them. And to deliberate is to stand up for the value of mutual respect, which is embedded in the practices of medicine and science and so on, but it is often taken for granted, rather than elevated.

I see Dan wants to follow up, and I will go from Dan -- I will keep track here -- and Anita. So we are open for questions and comments.

DR. SULMASY: First, thanks to everyone for very lucid and useful contributions.

One thing I was sitting here thinking about is the fact that most citizens are not going to be scientifically chosen to be part of one of these explicit mechanisms. And while it was valuable, for instance, for you to participate, and other participants, I wonder what ways there are of sort of increasing the sort of sense of legitimacy of this input on the part of the entire public. How do we get them on board? How do we have them -- are there ways to have them participate, or sort of feel that the people who are doing this are actually in some ways helping them to have some input into the process?

DR. GUTMANN: I am going to ask Dennis and Roland to answer that, because, you know, they have, obviously, had to -- it is part of their professional responsibility to think about that.

Dennis, would you begin?

DR. THOMPSON: Good question, because it is hard to answer. The experience, an example, of the British Columbia Citizens Assembly, which met for nine months to -- and had an actual official responsibility to recommend changes in the electoral system, it was a randomly-chosen group of citizens. And afterwards, they did get a majority in the referendum for the recommendation that the commission reached, but it didn't quite pass the threshold. And one of the reasons was that they didn't -- there was not an effort to get the rest of the public, who were not participants, to understand what had happened in the commission.

Some people were aware of that. I mean it wasn't -- obviously, it wasn't a

failure, because they got a majority. But there were some studies done afterwards that showed -- and this goes to your point -- that showed that if you can persuade citizens who did not participate that those who did are like them, they will then say, "Oh, I trust those people because they are like me, and because they went through a process that was fair and reasonable, and it exemplified mutual respect."

And there is actually empirical evidence that shows that that kind of trusting people like you in citizens assemblies worked -- at least it works in Canada. Maybe they are just nicer than we are. But -- and I could repeat other examples of that. So it is not a matter of getting -- it is not a matter of reproducing the exact same thing you do in Florence's group all over. It is letting people stand back and say, "Oh, well, I didn't do that, I don't understand the reasoning you went through, but if it is Florence," and people like the tattooed guy sitting next to you, "if they came to these conclusions, then maybe I should appreciate that."

DR. GUTMANN: So there may be a use for social media, and certainly the current technology allows more communication of two people who are like the people who are actually deliberating, so they know --

DR. THOMPSON: Yes, yes. Definitely.

DR. GUTMANN: Roland?

SIR ROLAND: Yes, it is a difficult question. I think there are two issues here. One is awareness, and the other is scale-up. So, in terms of awareness by other citizens that their fellow citizens are engaged in these processes, that is a question for which, obviously, there is mechanisms like social media. But it needs, I think, more emphasis.

And by contrast, in the UK -- actually, were pretty much discouraged from

spending money on that, and yet it costs to make people aware of what you are doing. I think you have to recognize that, and maybe include that as part of your strategy.

The second is scale-up, and -- because with these activities, they are intense, and you actually need small groups, although you can't have 25 small groups run together, that is expensive. You get some scale-up, because people talk to their friends, and so on, and are encouraged to do that in this process. To get the wider scale-up is difficult. You can have -- you can look in through, you know, Internet portals and the like, and -- which is related to the awareness question. But it is hard.

I think -- I may be being very naive here, but I think there is now an increasing use of these deliberative techniques. It is starting to become more common in different public and other bodies. And I think, over time -- possibly naively -- that mere fact will engender wider awareness and consciousness that it is legitimate and valuable. But that is a slower process.

DR. GUTMANN: Yes. Well, I think one of you said if you think dialogue is expensive, try conflict. If you think dialogue is expensive and time-consuming, try -- and discouraging, you know, of results -- try conflict and character assassination. You know, you add to this -- just characterize the -- what I would just suggest, when we make recommendations for research, they be comparative of education and deliberation to the status quo, because the status quo -- I will just speak in this country -- is extraordinarily expensive. We are spending money, and reaching results that are no results by the -- by universal opinion.

I mean -- and so we have to think about all the waste of not getting anywhere, compared to -- and then we have to find the most efficient ways of doing deliberation in education, to Christine's point. Most of the mis-education and

mis-deliberation isn't because people don't know the best way or good way of doing it, it is because there is malpractice. There is always malpractice. So we have to also find ways of getting people who are experienced doing it.

Anita?

DR. THOMPSON: Amy, could I just -- a quote, which --

DR. GUTMANN: Yes, please.

DR. THOMPSON: -- I can't resist.

DR. GUTMANN: Sure, sure.

DR. THOMPSON: From the former mayor of Lawrence, Kansas.

DR. GUTMANN: Yes.

DR. THOMPSON: What drove me to try structured, planned, public deliberation was my awful experience with unplanned, unstructured public engagement.

(Laughter.)

DR. GUTMANN: No, that is a great quote, actually. That is a great quote. That makes the point. Yes, yes.

Anita, we are going to go to 11:10, and take only a 5-minute break, because I think this is really important, and we have had such a rich group of presentations. Anita, and then Nelson.

DR. ALLEN: Thank you. I really enjoyed everyone's presentation: Dennis, your story; Sir Roland, your analysis, your three-part analysis; and the innovative board game; and the personal experience.

And originally, my question was going to be for Dennis, but then it became a question for Mrs. Evans. So I -- you know, I guess I would love anyone's thoughts, but here is the thing.

So we have in the United States this phenomenon of people standing on their rights, right? And so it often seems to me that, in contrast to a more deliberative mindset, we have this other mindset that is often portrayed in very heroic ways of standing on your rights. So an example would be this morning in the news the woman who is standing on her First Amendment rights in refusing to issue marriage licenses to gay couples, or, a few years ago, more tied to bioethics, pharmacists standing on their rights and not filling prescriptions for drugs they don't happen to believe in.

So, how do we think about how people in jobs where they have, you know, power over others, when their mindset is not deliberative, but is one of standing on their rights? And is one of the great benefits of deliberative democracy and education, ethics education, to get people not to stand on their rights, but to have a more participatory and collective mindset? So that is my question.

MRS. EVANS: I think that is really difficult, because the two examples you mentioned are very strongly felt by the people who have them.

DR. ALLEN: Yes.

MRS. EVANS: And it is -- to them it is more than just their rights, it is their whole way of living their life, which is pretty hard.

But I think that -- what I think is helpful is, when you are having a discussion where you have to come up with some other kinds of conclusions, is give the pros of thinking one way and the cons of thinking that way, and I think the consequences of each, so that a person knows what they are really considering, and then they would have a more educated response to what is being asked of them. They may not change their mind, but they will have more inside them to bring to their answer.

DR. GUTMANN: That is good. Dennis?

DR. THOMPSON: Anita has written about some of these things --

DR. GUTMANN: Yes.

DR. THOMPSON: -- but I think it is very hard, in a culture such as ours, which is pervaded by what I would call the John Wayne Theory of Ethics, you stand alone and do the right thing. And we are seeing some of that. How do you overcome it?

Well, let me say something a little bit controversial. Your group was apparently not -- was unusual, compared to the other groups, in that you were -- exhibit mutual respect. I think that the -- some of the deliberative poll groups don't actually -- are not designed in a way that would encourage taking collective responsibility for the outcome. That is why I tend to favor using deliberation in groups where you have to reach a decision. Even if it is just a decision for the group that nobody is going to interact, that gives everybody a sense -- we have got a stake in this, I really have to listen to you, and not just tolerate you or respect you, but we have got to work together.

And, you know, if the county clerk in Kentucky had thought -- had been in a group that city officials and city councils -- she might have realized that this isn't just a matter of what I think is right. Even if I am right, I have to work with other people.

DR. GUTMANN: So the point through isn't whether you can get the clerk in Kentucky to change her mind. The point is whether we have the resources to respond in a collective way, in a productive collective way, to that.

So I want to say two things about that that are very relevant to our Commission and recommendations. First of all, our Commission is a decision making body. We're not a policy making body, but we must do reports that give

recommendations, and it would not be helpful -- I think Dennis' example which I didn't know, we haven't written about this collectively, but Dennis' example is right to the point.

It wouldn't help if we said or all we did was report out our individual views. That would be totally unhelpful to citizens or policy makers. It only helps if we deliberate and come to some recommendations jointly as a Commission reflecting where we have disagreements and so on that we couldn't resolve, but making recommendations to suggest that there is a way that a diverse society can move forward on the policy level.

Now, coming to the standing on your rights, I think that's both great examples. Let me just take the most current, but it applies to the pharmacist as well.

The response that I think we could make, if we deliberated as a Commission on Bioethics, is: you can stand on your rights, you just have to step down from your job. That is, your job is an institution that has to recognize the rights of all Americans, and right now and rightly, the rights of all Americans, whether they are heterosexual, homosexual, are to get married.

Your right -- you have a right not to marry people, but then you cannot have your job. You have to step down from your job, because your job is to recognize the rights of all Americans to get married. That is your institutional responsibility.

And we haven't deliberated about this as a Commission. So the caveat is I'm speaking not as, you know, representing the Commission, but I am speaking in response that it would be a bad response from my mind to that as, you know, a philosopher to say you don't have rights. Of course you have rights. You have the rights of all other Americans.

But as you have taken on a public position and in that public position you have responsibilities and those responsibilities -- high among them is to respect the rights of all Americans, and one of the rights of all Americans, now constitutionally affirmed right of all Americans, is to be married.

DR. ALLEN: And the media --

DR. GUTMANN: And there may be sound bite ways -- there are sound bite ways of saying that.

DR. ALLEN: Yeah, yeah.

DR. GUTMANN: And it can be educational to engage in this as well because that clerk is not alone in her views, and we can respect those views as individual conscience, but respecting individual conscience isn't the same as allowing a clerk to refuse to marry people who have a right to be married.

DR. ALLEN: Right, and hopefully the deliberative education that we advocate --

DR. GUTMANN: Okay. We should move on.

DR. ALLEN: Yes.

DR. GUTMANN: And -- yes?

DR. DANIS: (speaks without mic) -- Florence talked about her group being unusual, and I think one of the things we've come to recognize is that the facilitator has an important role not simply being passive about it, and taking turns, making sure that everybody speaks up or has a chance to speak up, and doing things like organizing groups so that -- in places where we've worked with groups where women are hesitant to speak in the presence of men, for instance, you might have groups that are comprised simply of women and you aggregate the results.

And I think that the other thing is so striking that comes out from a successful deliberation is that it's not simply the facilitator that's making this happen. People in the group convince each other.

We've had instances where people start out saying, "I don't want to include mental health services. You know, I'm not mentally ill." Well, then you have someone --

MRS. EVANS: It's not about you.

DR. DANIS: -- someone will speak up and say, "I'm not mentally ill either, but I have a father who was mentally ill, and his alcoholism destroyed my family," and then it becomes less stigmatized, and the people in the group convince each other in a way that it's not left to the facilitator to do.

MRS. EVANS: In truth, our facilitator, I hardly knew she was there.

DR. GUTMANN: Nelson, did you have a question?

COL. MICHAEL: Really quickly, I think Marion actually just brought up really the question I was going to ask essentially Florence, but how do you develop -- I'm going to use the term from my own experience -- how do you develop a rules of engagement so that you can have a way in which people can have an open and deliberative and respectful process, but people are people, and you're going to have individuals that maybe didn't pass your scientific screen. They're going to be very opinionated and dominating, maybe they're misogynists, whatever the issue.

But how does a facilitator or how do other people in that group sort of normalize that behavior so that you can continue to have a process and not stop it by, you know, behaviors that are inconsistent with the process?

MRS. EVANS: We didn't receive any guidelines, no.

DR. DANIS: So we offer guidelines and we would say --

DR. GUTMANN: Yeah, we should go down the road on this, yeah.

Roland and Dennis on this? No, yeah?

SIR ROLAND: I'll just say I think the role of the facilitator is often undervalued. I think they're absolutely critical, and one of the things that we're looking at in our quality standards of public dialogue is obviously around that whole role of the facilitator.

The whole process from start to end has to be very carefully planned and managed.

DR. GUTMANN: I want to get back to something at the beginning. I think, Dennis, you said it, which is the importance of deliberation in standing bodies and among leaders and experts because we have a lot of established groups in our society represented by all of those three and four and five-letter acronyms, and I dare say -- am I accurate in saying? -- they're not all deliberating most of the time.

So what more in bioethics can we advise for deliberation among leaders, bringing in, when appropriate, members of the public? This is a panel, for example, which have a number of people who are professional experts in this area, and you add tremendously to it. So what more could we recommend in this regard?

And I'm going to begin with Dennis and go down.

DR. DANIS: I mentioned briefly the professional associations, which are a fairly easy target, and now you might point out that had the American Psychological Association deliberated a bit more about their policies on whether psychologists' ethics rules should restrict or restrain the conduct of professional psychologists working with CIA and other, they might have avoided what's been a disaster for the association, as

well as for a number of other people.

There are other professional associations, even economists actually had sort of a faint-hearted ethics group that came up finally with a code. So to reach those decisions, they quickly learned that they had to deliberate. So you could recommend something along those lines.

The Institute of Medicine now, quite a few years ago, 1995, you may know, issued a report which called for more deliberation. That was its main point, multi-tiered deliberation, and it listed a whole bunch of associations and groups.

This was a very good report, I think you'll agree, because one of its recommendations was to reestablish the Presidential Commission on Bioethics. So I would suggest the Institute of Medicine or somebody ought to actually update or do another report. Where do things stand? What happened to those recommendations?

And then I think maybe John Gastil will this afternoon -- I hope he will anyhow because he was one of the editors of a recent book called "Democracy in Motion" which lists a lot of activities going on, a lot of organizations that, you don't have to name particular ones, but that could be encouraged to actually, in their own interest, do some deliberation about bioethics issues to reach collective conclusions that would benefit us, inform policy makers, and otherwise advance the cause without having to set up a lot of expensive, new institutions.

DR. GUTMANN: Yes. Because I don't want us to focus overwhelmingly, let alone exclusively, on things that you just have to get created from scratch or that are enormously expensive when there are existing organizations that, if they became more deliberative and more inclusive, it wouldn't cost them much, if anything, more and it would do all the things, Roland and Marion, on your list, you had

-- the legitimacy, the productiveness, the helpfulness for policy makers. So that would be terrific.

I should report that, before we conclude, that we had recommended in our neuroscience report and we had recommended in our deliberations that the group that NIH set up to move neuroscience forward, since the initial charge from the President, from President Obama, said that he was very interested in making sure that this be an ethical enterprise moving forward and take ethics into account as neuroscience moving forward, we had recommended that people who are expert in bioethics be included in the advisory groups because we had noticed that none were included.

And recently -- and I'll turn it over to Christine -- we found out that a subcommittee on bioethics in neuroscience was, in fact, created. And so, Christine, could you just say something about that?

DR. GRADY: This is part of the Brain Initiative, and so they -- what's called the Multi-council Working Group on the Brain Initiative that's housed at the NIH and brings in scientists from all over the country -- they decided to establish a working group, a sub-working group of their group, specifically to focus on neuroethics, and it's just being set up and, you know, we'll see how it goes, but it's in direct response to the recommendation that the President's Commission made.

DR. GUTMANN: And it's very promising for many reasons, but none more so than the fact that Christine Grady is co-chairing it.

So before we adjourn this session I just want, on behalf of the entire Commission and everybody present, to thank all of you for a most productive and informative set of presentations. Thank you so much.

(Applause.)

MRS. EVANS: Amy?

DR. GUTMANN: We're going to break for five minutes and then reconvene.

Yes.

MRS. EVANS: I was thinking about Nelson's question to me.

DR. GUTMANN: Yes.

MRS. EVANS: Okay. I think that the guide -- well, I said we didn't have guidelines, but the goals were clear. We were not to come up with a decision.

DR. GUTMANN: Right.

MRS. EVANS: So that influenced how we spoke.

DR. GUTMANN: Right.

MRS. EVANS: Nobody was promoting a certain view.

DR. GUTMANN: Right, right. Thank you. That's very helpful.

(A brief recess was taken.)