

Full Committee Discussion on Genetic Discrimination
Facilitators: Agnes Masny, R.N., M.P.H., M.S.N. and Reed V. Tuckson, M.D.

DR. TUCKSON: The floor is open for some discussion.

By the way, I do want to say that we actually don't quite work for the administration. We are advisory to the Secretary, so that gives us a little more latitude. I'm glad that you sort of put that there so that we can underscore, particularly for the new members of the committee, again, that we are an advisory group to the Secretary.

There are certainly some constraints there, but there are multiple opportunities there. The floor is now open.

Ed, I see your hand.

DR. McCABE: First, I want to thank you for coming and presenting. Please take our thanks to your boss as well for sponsoring this bill. This is something that has run in the six years that I have been involved on advisory committees, it has been one of the top issues for both administrations and each of the Secretaries. Or at least we have taken it to each of the Secretaries. So please thank your boss for sponsoring this.

You gave us some guidance in terms of how we could help. The opposition, the opposition you said you think they may go neutral on this. Is there anything that needs to be done in terms of getting more support from appropriate business friendly groups to help with this?

MS. VICKERY: We are actually working with those groups, like I said before, and they probably have about ten concerns. There are certain things that we are having to sit down and negotiate with them. There are some things that are not negotiable. It is a matter of finding something that people can live with on both sides of the aisle.

Basically our strategy right now is to get as many people on as we possibly can. The more people you have supporting this bill, the harder it is for groups to oppose it, politically and PR-wise. So that's our strategy right now, focusing in on bringing people in, any sort of constituency within their district of people who are affected by this.

It is very hard to say no to people from your district, and it's very hard to say no to sick people.

DR. TUCKSON: Yes?

DR. McCABE: As a follow-up to that, for those of us who are rotating off of the committee, when is our last day of service? Is it the end of this meeting? Okay. Thank you very much. Because I'm taking a mini-sabbatical. I have met the representative who is a Republican for the district in which I have a small business in Colorado. I may pay him a visit then as I start my sabbatical.

MS. VICKERY: Come see me, and we'll get you everything you need to go in and meet with him.

DR. McCABE: Thank you very much.

DR. TUCKSON: Agnes?

MS. MASNY: As I mentioned earlier, one of the options that we have is we actually have 150 of the CD-ROMs of the testimony from the public. Maybe what we could do would be to identify the people that were previewed in this public comment, what areas they came from, and specifically send it to those representatives, and of course maybe to all the House members as well.

We can't send it, of course, but we can recommend that the Secretary of course send it onto them. But maybe we could highlight what areas those people who spoke, what areas they came from.

DR. TUCKSON: Great. We've got in the queue Francis, Emily, and Julio.

I just want to make sure, though, that Jaimie has been given a copy of the letters that we have sent to the Secretary already. If we have not, Jaimie, if you don't have those, I'm going to see if somebody has a handy copy somewhere around and they can hand it to you so that you can take it with you before you go.

Obviously we're thinking about now what is the next step. But I want you to know we have been pushing hard in that regard.

Francis?

DR. COLLINS: I would also like to express my thanks to Representative Biggert, and to you, Jaimie, for being here today to tell us about the status of this. Having worked on this issue, some of us for more than a decade, it is gratifying to see the activity that's going on this year with the unanimous vote in the Senate, and now the bill being introduced in the House, and at least assigned to committees, although I guess I'd like to hear a little bit more about your impressions about whether hearings are likely to happen. Without them, it is generally the conclusion that not much forward motion is going to be occurring.

I must say I'm deeply disappointed to see the opposition that seems to be largely responsible for the current logjam coming from the business community. After all, as pointed out in the nice presentation by Peter, a very large number of states have passed legislation that prohibit the use of genetic information in hiring, firing, and promotion. To our knowledge, there has been not a single instance where that legislation has led to frivolous lawsuits, which I think has been one of the community's concerns coming from the Chamber of Commerce and the National Association of Manufacturers.

So the evidence for this being a risk to their business practices does not appear to be very compelling. The argument for the need for this is nicely outlined in the testimonies we heard here and reproduced on the DVD. From the public's perspective, it is really very compelling.

So I guess I had two questions. One is what is your estimate about the likelihood of hearings. The second relates to rumors that one has heard that perhaps the bill would have a better chance if the employment provisions were stripped out and it was reduced simply to a health insurance protection.

I just want to comment that I don't think that is what the public is looking for. If people are anxious about genetic information and how it might be used against them, employment is clearly a serious issue. It is not just about health insurance. I think that would be unfortunate to see that particular part of the bill lost in this particular shuffle. So maybe you could comment on whether

SACGHS Meeting Transcript
June 15-16, 2005

that particular idea of recrafting the bill to limit it only to health insurance is something that's likely to have any legs at the moment, and as well if you could comment about hearings.

MS. VICKERY: To answer your second question first, there has been legislation introduced previously that was just health insurance. I'm not entirely sure that that is something that Ms. Biggert and Ms. Slaughter are amenable to. From what we've heard, the insurance industry is not nearly as opposed to it as the business community. So it would be easier to do. But I guess it comes down to the question of do we want what we need, or do we want what we can do?

I think from everything that we've heard, the employment arena is where the problems seem to be cropping up. I think that we certainly need to address the employment issue as well.

To answer your first question about committees. From what I can tell, the committees are more open than they ever have been. Certainly Ed and Workforce had a hearing in July. It is hard to say what committees are going to do and what they're not going to do. A lot of it depends on what else is on the slate, and the timing.

All I can say is that we're working on this, and they seem to be more amenable to moving this bill than they have in the past.

DR. TUCKSON: Good. Thank you.

Let me just make sure that I understand also, Jaimie, in this regard. Is there any active discussion with the employment community, are there ways in which the bill can deal with their concerns regarding frivolous or unnecessary lawsuits? It is not even, as I understand their position, we did a lot of work listening to them very carefully. They were very generous about their time and helping us to understand it.

As I understand their position, just as the public is concerned about the potential fear issues, they are concerned about the potential of frivolous lawsuits, which is important to their conduct of their activities.

Is there any sense of sensitivity to those concerns? Is there any way in which the bill might modify or in some way take into account those concerns?

MS. VICKERY: And that was something that was brought up with the Slaughter bill in the 108th Congress. If you look at the current bill 1227, there are some provisions in there. There are certain steps that have to be followed before you can take a claim to court.

Also, it is broken down into three categories, the amount of awards that can be received. There is a limitation on awards based on the size of the company. So obviously if you have a problem with IBM, IBM is going to be able to take care of that claim much more than a mom and pop bakery or something.

We are still open to negotiating with them. Like I said before, it's a matter of finding that balance between still having some effective enforcement mechanisms and some teeth to the law, and at the same time, finding a way to make it work for business people.

DR. TUCKSON: Thank you.

Emily?

SACGHS Meeting Transcript
June 15-16, 2005

DR. WINN-DEEN: So I think one of the things this committee has tried to do in the past to move this legislation forward was to understand what the objections were. What we had heard previously was there were two objections.

One was that it's not really happening. We have testimony, we have a DVD. Please use these tools. The other comment we heard was there is adequate protection under the law. We commissioned a report to really review that in a very analytical way to look at what actually are the existing protections, and to create a set of data that could be presented, again, in a very analytical way to individuals who are making those kind of just brush it off kind of comments, we don't need to be wasting our time with this. There are other things to be taken care of.

Are there any additional points that we could address very specifically through the mechanism that this committee has, which is basically public comment and the ability to commission special reports of sort of the state of the state that would be helpful at this point in time to move the legislation forward?

MS. VICKERY: I think that report is going to be phenomenally helpful. Again, like you said, again and again, people are saying there are existing protections in law. It is HIPAA. HIPAA takes care of it. ERISA is fine. There are already protections in the law.

But to be able to present them in a very concise way and say this doesn't cover this, this doesn't cover this, this doesn't cover this, is going to be tremendously helpful. If there was some way to send that up to the Hill in a very concise format that staffers could look at and that we could use would be incredibly helpful in getting people to understand that there really is no legal protection.

DR. WINN-DEEN: Okay, and the other question I had for you is of the individuals who have not yet signed on, have they not yet signed on because they just have not yet really been educated and come to a decision? Or are they not signed on because they are opposed for some specific reasons?

MS. VICKERY: I think it's a combination of both. We have certainly, health staffers are overwhelmed. This stem cell issue on the Hill consumed everyone for the past three months it feels like. So as that settles down and people are starting to move on from that, I think this is a prime time to educate members on the importance of this legislation.

DR. TUCKSON: I just want to clarify one thing that I think you just said in response to Emily. Sarah, let me make sure. I want to make sure that I heard clearly.

I think you alluded to it, but I want to make sure you were specific. Did you actually request that we send your office a copy of the analysis that we have done?

MS. VICKERY: That would be incredibly helpful. I would very much appreciate a copy.

DR. TUCKSON: I just wanted for the record to note that we had been asked to send a copy of the report to the Congresswoman's office. We will be happy to do so. Thank you for the clarity.

Julio?

DR. LICINIO: I have a question on the same issue. Where does like a preexisting condition, where does that begin? Where does it overlap with actual genetic testing?

SACGHS Meeting Transcript
June 15-16, 2005

In other words, you can get genetically tested and be shown to have a predisposition to a disease that you don't have yet, or you could already have the disease and also have the gene.

Then for preexisting conditions, health care has been traditionally problematic. Does the genetic testing that's discussed in the legislation overlap with this issue of preexisting condition? In other words, are we talking about only the test for someone who is healthy, or a test for someone who may already have a condition?

MS. TURNER: I'm from the Labor Department, and maybe I could just speak up. I know that may seem kind of random that a Labor Department person is speaking up, but I think when Peter gave his presentation, he talked a little bit about the HIPAA portability provisions and protections they have against sort of in health insurance and self insured employment based coverage plans restricting coverage based on the fact that a condition is preexisting.

I think the analysis that was done supports the finding that preexisting conditions, once you actually have a diagnosis of a condition, I think you are pretty clearly within the HIPAA protections. What is unclear is if you don't have a diagnosis of a condition and there is just genetic information, there are still a lot of gaps there, and I think that is what the legislation is looking to address.

So there is a question whether or not an attending provider or a licensed medical professional has actually diagnosed a condition. Then I think you cross the line into a preexisting condition, and certain protections apply. It's up until that point that there are a lot of gaps that I think the legislation is trying to address.

DR. TUCKSON: Aren't our ex officios terrific? Yes?

DR. LEONARD: Can I clarify whether the request is for the legal assessment report, or whether you are also requesting our telephone book of the public comments, and whether you have that already, and whether that would be useful for distribution?

MS. VICKERY: I would actually like both. I'd appreciate both of them.

DR. TUCKSON: We appreciate that we are very clear in what the request is. Thank you.

DR. McCABE: I would just encourage those who speak on this issue include it in your talks. One of the first things I did when we received the telephone book in my office was take a picture of it so that one could see the thickness of it. I think this has been an issue. Why develop legislation when there is no discrimination.

I was on record at the last meeting for saying that the individuals who have written, and they are geneticists, my colleagues, who have written that this is a non problem should be ashamed of themselves. I received comment back from them arguing that I should not say that. But I'll go on record again and say it. They should be ashamed.

It's like when you catch the fox in the hen house and ask him what he's doing there and he says he's just visiting. Then why does he have blood on his cheeks? He says, I cut myself shaving. You don't ask the insurance companies whether they are discriminating. What did we think they were going to say?

SACGHS Meeting Transcript
June 15-16, 2005

DR. TUCKSON: Let's do this. By the way, Ed, there are a couple of folks who are sort of wanting your picture. Not your picture, but the picture you took. They probably want your picture, too. If you would send that around to the team, I think everybody would sort of appreciate it.

Well, as we bring this portion of the meeting to closure, let me try to get, and again, we've got just a couple of seconds before the break. I want to make sure that we're clear on next steps here.

I think the committee has gone pretty far in terms of what it can do. The Secretary now has the materials that have been referenced. He has the letter. We will of course use every mechanism to keep that in front of him for moving forward.

What I want to sort of get a sense of is is there anything else left? I still would say to you, Ms. Vickery, that if there is any role that we can play, and I'm not volunteering or think that there is, but to help try to, again, look at some of where the "opposition" is and common ground, trying to, again, get some language that helps to mitigate some of the concerns that they have that are not related perhaps to the issue, but perhaps more of the unintended consequences of the issue.

That's really what I think I'm hearing a large part on that community. It's the unintended concerns about the legislation. If there is a role that we can play in terms of brokering, talking, clarifying, I mean, I think we really want to get there. So know that the committee is open to whatever role that we can appropriately play within the confines of our charter and responsibility.

A couple of quick thoughts then to get us if we have some other next steps.

DR. LEONARD: From Agnes' comments, did we specifically ask the Secretary to do a broad distribution of the public comments and the legal analysis?

DR. TUCKSON: Let me just reread the letter real quick.

DR. LEONARD: Can we do that? Or recommend it? Ask it of the Secretary?

MS. CARR: Actually, Dr. Zerhouni, in transmitting the recommendations of the committee, suggested that the Secretary do that.

DR. TUCKSON: Good. Hunt?

DR. WILLARD: Just a point of clarification. Can we or can we not as individuals contact our representatives? Especially those who might be on the wrong side of this particular issue, as long as we don't make reference to the fact that we're a member of this advisory committee.

MS. CARR: Yes, as long as you don't do it today or tomorrow.

(Laughter.)

DR. TUCKSON: All right. Yes, last comments, Agnes.

MS. MASNY: In our last summary, we had made a recommendation to the Secretary that he pull together the stakeholders to actually analyze some of the concerns from the business community. I don't know if that has been moved on, or if we could make another attempt to say something to that effect.

SACGHS Meeting Transcript
June 15-16, 2005

Just to mention that in the reports and public comments that we've had on the coverage and reimbursement issues, there were several professional organizations and business organizations that voiced their support for the antigenetic discrimination legislation, one of which was the American Academy of Actuaries, the other the American Association for Clinical Chemistry.

I'm just wondering whether we should kind of go through that report and pull out even some of those comments. If we were going to send on another report from this meeting, to sort of even say that we've received even further comment from the business community, and that maybe some of these organizations could be included in the stakeholder meeting, if in fact that is where that would go.

DR. TUCKSON: All right. It's a good suggestion. What I'm a little bit, what I'm hoping is you'll give us a little leeway to analyze the situation in terms of the Secretary is still fairly new, and there is a lot of paper bombarding his office.

Our report is pretty voluminous and pretty specific, and it is pretty recently there. It was also with Dr. Zerhouni's transmittal letter. Let us try to work the system as well as we can to make sure that our stuff is getting onto his desk.

I'm a little concerned about just sort of bombarding him anymore with any miscellaneous parts, because it may take away from the sense of what we've got there. It's a great suggestion. Let us use it with flexibility. I assure the committee that we will do everything we can to make sure that our stuff is in front of the Secretary and owe you a report afterwards. I'm not sure there is anything else to be done. Yes?

DR. McCABE: In 48 hours, several of us will not be as constrained as the rest of you are. I know that I would volunteer to be of any assistance that I could be, and I'm sure the others would as well.

DR. TUCKSON: Well, thank you all very much. Ms. Vickery, if you will keep us connected to what is going on, especially to our staff team as we monitor this. We have regular conference calls and subcommittee reports, so we're more fluid than, you know, the next meeting in October. So let us know what we need to know.

Thank you all very much for a good discussion.

The drill is -- and by the way, I keep alluding to the new folks because you all don't know how crazy the chairperson is -- we start on time. So 10:30, if you're not in here, oh my God, the woe that will befall you. So 10:30 exactly.

(Recess.)