

Roundtable Discussion
Facilitator: Ms. Berry

We're now going to have a roundtable discussion, and Cindy Berry is going to lead that discussion.

MS. BERRY: Welcome, Kristin. Good to see you. Thank you for being here.

I'll kick it off with one question. I have a few others but I want to pass the mike around, so to speak, because I know people are very interested in this issue on the committee.

We are hearing and have read about in the media some angst, I guess, among some folks in the business community about this legislation primarily. At least I'm hearing that this isn't really necessary because it's kind of a remedy in search of a problem and the problem doesn't exist. In this committee we have heard a lot of testimony and were presented with a lot of information indicating that the problem isn't necessarily evident, that people have a certain fear factor and therefore don't seek the appropriate genetic services that they may need out of a fear of discrimination. It's not that the discrimination has necessarily occurred, but it is serving as a barrier to important services.

Is that the only opposition that you're hearing? Is there a major objection or several objections that are being raised to legislating in this area beyond that, beyond the issue of, well, it's not really a problem?

MS. FITZGERALD: Well, I think anytime Congress moves forward on legislation, they want to be sure of the problem that they are solving or of the consequences of the actions that they're taking legislatively. So I would say that there are some who are looking at the track record or lack of track record compared to the other -- I know there have been some cases of genetic discrimination, but compared to the track record of the other employment discrimination laws that we also might have looked at. There are some that are expressing concerns about that.

I think that employers and all parties who will be impacted are taking a look at the legislation and evaluating it and trying to ensure that they understand it and trying to ensure that they understand the impact. I think that discrimination legislation is always well meaning, and I think that Congress may not have anticipated some of the suits that have come out of various discrimination laws that we have in the past. So I think in this particular case, it's all the more difficult to anticipate just understanding the science.

So I think, rightfully so, we want to be sure that we are crafting this correctly so that it would address the kinds of things that need to be addressed and not sweep in other kinds of consequences. So I think that in terms of an evaluatory process, I think all the Congressional members are going to go through that, and I think they'll hear from the employers and they'll hear from others. But for our own sake I think we have to better understand the law and the state of the law and the way the new law would interact within itself even, to see how we can make sure that we know what we're going to get out of it the best that we can.

MS. BERRY: Sure. Well, as just a quick follow-up to that, you identified several issues that you think the various committees, particularly your committee, are going to examine to that end.

MS. FITZGERALD: That's not by any stretch an exhaustive list. I just gave a few examples.

There are certainly a lot of things that we're looking at, and I think the other committees as well.

MS. BERRY: Is there, though, any glaring problem or one area in the Senate bill that's creating serious difficulty or angst among members in the House that you're aware of? Is there some real major concern that we should be aware of, or is it just a series of all these very important items which, once you examine them, you have the sense that we can work through them?

MS. FITZGERALD: Yes, I think some of the stuff I had mentioned in terms of the EEOC enforcement and the amount of damages, I think had those things stayed in the bill, you are absolutely right, you'd have a bull's eye on there where folks would be saying we cannot move forward because of this. I don't think that's the case here. I think that it's more folks are looking at all the impacts of the legislation and all the various parts of it. I don't think that there's one particular thing where folks are saying we cannot surmount this particular provision or something.

MS. BERRY: Ed?

DR. McCABE: Ed McCabe. I'm curious, and you may not know the answer to this, but given that the employers made their feelings known on the Senate side and yet the vote was unanimous, I'm wondering, assuming that the employers did make their opinions heard, then why there were no votes against the Senate bill.

MS. FITZGERALD: I couldn't speculate as to the Senate processes, but the House is different than the Senate. I mean, I think that there is, like I said, a lot of support for making sure that people aren't discriminated against on the basis of genetics. But I think our process will be different, and that's why we're the House and they're the Senate.

DR. McCABE: Can I have a follow-up, then? The other thing that I heard you make an analogy to other civil rights legislation, and I've heard that as well. So this is felt to fall within that genre of legislation, that it is civil rights legislation?

MS. FITZGERALD: Well, I think that parts of it are. There are two titles to the bill, as you know. I know that you are very familiar with the bill. But I think that the health insurance title would be similar to the HIPAA non-discrimination. I mean, it amends HIPAA. Then the legislation on the employment side is modeled after the Civil Rights Act. I mean, they've used the language directly from it. So I think it's most similar to that.

MS. BERRY: Hunt?

DR. WILLARD: Hunt Willard. I'm not going to try to understand the nuances of how things work in Congress. I'm having enough trouble today.

(Laughter.)

DR. WILLARD: But I do know enough to ask the question of whether this has -- and, of course, we wouldn't dream of quoting you on this, so feel free to just tell us --

DR. McCABE: This is being Webcast. The camera there is --

MS. FITZGERALD: Thanks for telling me. Now you tell me.

(Laughter.)

DR. WILLARD: -- whether this in fact has the support of the House leadership so that there's any sense that someone is trying to drive this to the Floor, or whether this will languish for a while. I guess the comparison question for that is whether there's any sense that the electorate is paying attention so that that will force this because someone will finally say, look, the Senate is 100 percent behind this. What's the matter with you guys in the House? Who is holding it up? And, by the way, we vote next fall.

MS. FITZGERALD: I wouldn't necessarily say this is an electorate-driven issue. I think that there are certain issues that are like that. The Patient Bill of Rights comes to mind, just because I'm thinking about health legislation. This isn't necessarily one where a member is going to go back to his town hall meeting and get barraged. There are certain issues like that. I'm just thinking of lots of different things. This is more complicated. So it's not quite in that same level there.

In terms of the leadership, I think that the leadership is wanting the committees to go through their process, go through the regular process, have hearings, investigate, hear the concerns of folks who are concerned and hear the support from folks who support. I think that they think that's a helpful process to get the members educated as to where we are. Like I said, the Senate had acted on this in the past, so they were a little bit more cognizant, whereas the House hasn't passed legislation like this recently or ever since HIPAA, and I think it will take a little bit of time just to spend the evaluatory time we need to look at the issue.

So I think it will progress based on the committee process, the way that much of the legislative process goes through.

MS. BERRY: Kristin, I don't know if you have a sense of this or you can handicap it, but do you think that it's possible or likely that a bill would pass the House before the end of the next Congressional session sometime next year?

MS. FITZGERALD: You know, I'm so bad at handicapping. I was giving a speech earlier and I said I handicapped one particular issue all year last year, that it was for sure going to happen, and it didn't happen. So it's so difficult to predict, and I think that part of that is that the process will be serious and that the members will really be studying the issue. So I think that will determine the outcome. To the extent that they feel there's a compelling force that we must move forward that year, then it will. If it's something where there's a sense that they need additional time, then they'll take additional time.

So I think that's kind of what we'll see out of the committee process. Like I mentioned, it's not just one committee's process. Remember, it's three. So each of those committees will have to work their will.

MS. BERRY: Any other questions from anyone on the panel?

(No response.)

MS. BERRY: I guess not. Hearing none --

DR. McCABE: Well, thank you very much for coming and speaking to us. This is an incredibly important issue for us. It was the first letter that the Secretary's Advisory Committee on Genetic

Testing sent to Secretary Shalala and to Secretary Thompson, and the first correspondence we had with Secretary Thompson with this committee. So it has been a priority for this and our predecessor committee, so we really appreciate it. We may ask you to return at some time in the future to update us assuming that it doesn't pass in the next two weeks.

(Laughter.)

DR. McCABE: As you have predicted, though, with your other experience with handicapping, maybe you'll have this one in error also.

(Laughter.)

MS. FITZGERALD: That's true. That could happen. You're right.

DR. McCABE: But we really appreciate you working on this, and we appreciate the House taking it seriously too. This is something that we think everybody must agree upon and really know it's the right thing to do. So we understand that process and we endorse it. Thank you very much.

If there are no other issues, then we will adjourn until tomorrow. I'll remind you that the instructions for dinner are in your packet. For those of you who are joining the group for dinner tonight, we will meet in the lobby at 6:45. Our reservation is at 7:00, and we have to take cabs, so please be there at 6:45. If you're not there at 6:45, bring your flyer and get your cab on your own and we'll see you at the dinner.

Thank you very much. I look forward to tomorrow.

(Whereupon, at 5:22 p.m., the meeting was recessed, to reconvene at 8:30 a.m. on Thursday, October 23, 2003.)