

Update on the Status of Federal Legislation to Prohibit Genetic Discrimination
Report from the U.S. House of Representatives
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So now we're going to turn to an update on the status of federal legislation to prohibit genetic discrimination. We're delighted that Ms. Kristin Fitzgerald, who is with the House Committee on Education and Workforce, is here to brief us about prospects for passage of genetic anti-discrimination legislation by the House of Representatives. Ms. Fitzgerald has worked on Capitol Hill for almost 10 years. In June of 2001 she joined the staff of the House Committee on Education and the Workforce, chaired by Representative John A. Boehner of Ohio, and has primary jurisdiction over employer-sponsored pension and health benefits.

Before joining the Committee staff, Ms. Fitzgerald held leadership positions in government affairs and directed grassroots efforts for the Health Care Leadership Council, a coalition of the nation's leading health care companies and institutions. In addition to genetic non-discrimination, the focus of Ms. Fitzgerald's work during the 107th and 108th Congresses has been the Patient's Bill of Rights, the Mental Health Parity Act, the Pension Security Act, and the Small Business Health Fairness Act, among other issues.

Ms. Fitzgerald will give us a brief history of the House's actions on genetic discrimination and give us her perspectives about the Senate bill and how the House will proceed. I'd just like to point out for Ms. Fitzgerald what I mentioned earlier today, and that is that this has been a leading priority for this committee and our predecessor committee, the Secretary's Advisory Committee on Genetic Testing. So this is a very important issue for us, and thank you for coming this afternoon.

MS. FITZGERALD: Well, thanks for having me, and I would like to compliment you on your timing. When you first talked to me about speaking, I thought, oh, this is going to be really easy because I'm going to say, well, the House is likely to follow the lead of the Senate until the Senate acts.

Well, lo and behold, one week before the speech we have the Senate passing the legislation on genetic non-discrimination with a vote of 95 to zero. So it's really nice timing, and it's good timing I think for you all to focus a little bit on the House side.

Definitely the Senate's actions have vaulted this issue to the top of our list. I hadn't heard too much about the issue this year, but the day after the Senate passage, or even the day of the Senate passage I feel like my desk is -- every person that calls, that's what they're calling about and they want to know what we're thinking and what our views are and all those kinds of things. So it has definitely become an issue that I think we're going to be spending quite a bit of time on.

In terms of talking about the House perspective, I think it's easier to do that by talking a little bit about the background on both the House and Senate sides. This is not a new issue, as you all know. There are lots of different state laws that focus on this area in all different aspects of it, the privacy aspect, the insurance aspect, the employment aspect, and Congress has also looked at it in the past a little bit with the HIPAA law, the Health Insurance Portability and Accountability Act that prevented discrimination on a number of different health status factors, but including genetic

information.

That was probably the first time on the House side that legislation passed that addressed it in terms of the discrimination aspects of it. The Senate has been a little bit ahead of the House in looking at the issue. Both times that the Patient Bill of Rights passed, I think two years ago and maybe three years ago, or maybe it's two and four, I'm not exactly sure, it kind of all runs together, but they adopted amendments that would have, addressed this in the health insurance area.

I think the House had not spent as much time on it, although admittedly on both the House and Senate sides there was legislation sponsored by Representatives Daschle and Slaughter that would have prohibited genetic discrimination in employment and in health insurance, and those had quite a bit of support from rank and file members of Congress, both on the House and Senate side, but particularly on the House side.

I think the issue or the actions that really sparked the House's attention was the President's radio address in, I think, June of 2001 where he talked about supporting legislation that would go forward and that would protect genetic privacy and ensure against discrimination, and that really caught the House's attention, and shortly after that address there were three House hearings, two of which were at the Education and Workforce Committee and one at the House Energy and Commerce Committee.

But the hearings, I think, investigated the state of play, looked a little bit at the science, looked a little bit at the current laws that there were and how they did and didn't address the issue, looked at the current proposals, at that time the Slaughter bill and the Daschle bill, and how there may be impacts of those particular pieces of legislation, unintended consequences, those kinds of things. Then the Senate has gone on from that, and I know this isn't news to you all but they've spent an exhaustive amount of time working on this bill. I think they negotiated probably two years to come up with bipartisan legislation that had the support of all the Senate and the President to prevent discrimination.

So it's not surprising to me that the Senate acted because they've spent a ton of time on it and they voted on it in the past, and it is sort of a more mature issue on the Senate side being that they've considered it several times.

The House, we're a little bit behind on this, but I think we're starting to catch up. I think members of the House see this as a unique issue both on the employment side and on the health insurance side. Typically when I work on health care issues, there's often very strong feelings on both sides, a lot of opposition and then a lot of support. But people who are opposed in viewpoint on this particular issue, I think that everyone believes there shouldn't be discrimination on the basis of genetic information, and so there's agreement, and it's the same kind of thing on the employment side.

People do not believe that there should be discrimination on the basis of genetic information. That's different than when we've acted in the labor area before and in the health care area before. It's just there's a lot of folks that are in agreement about the goals, and I think that's a positive thing about the issue.

Another area where it's a little bit different than perhaps past actions is that when Congress has acted, particularly on the employment side, to ban discrimination, for example, on age or race or religion, there has been typically patterns that they're trying to rectify. If the Congress goes

forward in this area, it seems as if we're a little bit on the protective side before there are huge discrimination cases, that kind of thing. Congress will be moving forward in an anticipatory way to protect people on the basis of their genetic information, and that's a little bit different than perhaps other types of labor laws that we've looked at in the past.

I think another area that is unique about this that is a challenge for legislators is just the science, the fact that before we even have ink dry on any kind of bill, the science will have changed and will continue to evolve, and these statutes that we're looking at as models, they tend to be, particularly looking at the civil rights laws, ones that stand. I mean, we're not spending a whole lot of time every Congress going in and reauthorizing, for example, as we do in some areas. They are the laws of the land and far reaching. So it's a little bit more complicated looking at this issue, simply because we know we don't understand the science and that it will continue to evolve. So you just have to have legislation that's nuanced enough to anticipate that.

I think right now what the House is doing is evaluating the Senate legislation, and I think that, first of all, the House looks very positively on the effort that went into the Senate bill. I know that my counterparts on the HELP Committee, they have shared jurisdiction over a lot of our same issues, worked very hard and very diligently for a long time to rectify a lot of concerns that folks had about past legislative proposals, and I think some of the areas where they definitely made improvements that we had been concerned about are, for example, on the employment side, just following the patterns that we've set with regard to EEOC enforcement and damages and sort of conforming them to the way the other labor laws look in that area.

They looked at the issue of disparate impact, whether or not there would be disparate impact suits allowed. That was one that we had pondered a little bit in looking at the Slaughter legislation in the past. It seemed to us that were you to allow a disparate impact suit, that you were actually in effect creating an incentive for an employer to know genetic information to protect against such a suit. So I think it was very positive that they were able to look at some of those issues and come up with solutions that would prevent those kinds of things.

I think they also made improvements on the health care side. The Slaughter bill and the Daschle bill had really tight use restrictions that we were concerned about. For example, you could use the information that you had to pay a claim, but if you were subrogating a claim, that was not quite payment of claims, and different kinds of things. I think the HIPAA privacy regulation had spent a long amount of time working out what uses were allowable for health care information, not to disclose but in order to use the information for those kinds of things. I think it was important and good that they tried to conform to the HIPAA privacy reg where they could.

I think they've also gone a long way to try to look at the dual regulatory issues. I don't even know if you can say dual. It would be more like tri or quad regulatory issues that you come across when you're working with a lot of different agencies that are overseeing various people but with similar kinds of responsibilities, and where you have a little bit different kinds of restrictions here in privacy, a little bit different here in the bill. I mean, those are things where the regulators are really going to have to work together, and I think they've done a good job trying to anticipate that.

I think that the House is still, though, looking at the Senate legislation and trying to investigate all of the various details about it. For example, we're looking a little bit at how exactly you cross over when you have a new piece of legislation that has a health title and an employment title. We haven't done that in the past. You can make crossovers with the Americans with Disabilities Act and, for example, the Mental Health Parity law that Congress did, or even the HIPAA law. But they weren't adopted in this model where we set forth and said this is one title and this is how

we're going to deal with an employer when they're an employer and this is how we're going to deal with a health insurance plan. So that's something that we're looking at, just how exactly those kind of work together.

I think that we also are still looking at how the bill does interact with both the HIPAA privacy reg as well as the HIPAA protections, the way the Congress protects and the way the law protects folks who have health status factors, how this will impact group premiums, for example, because it does make a change there, those kinds of things. We're taking a look at that. I think we're looking a little bit at how genetic information, how genetic tests, all those kinds of things, how they're defined and how that will impact someone's current medical information, as opposed to what might be some kind of predictive information and just kind of what the interplay will be with the various titles of the bill in terms of those definitions.

I think another aspect of the House that is a little bit more complicated than the Senate is the issue of jurisdiction. Over on the Senate side, the HELP Committee has jurisdiction of the bill and they've done a great job working out their version of it. On the House side, we have three committees that have jurisdiction over the bill, the Ways and Means Committee, the Commerce Committee, and our committee. We have jurisdiction over the health title and the labor title. The other committees focus on the health titles.

But any time you have more cooks in the kitchen, it takes longer to develop the recipe. So I think that will be a factor also in the House, that all the committees have to take a look at the bill, all the committees have to ask their questions, all the committees have to evaluate the consequences of various parts of the law. Those other committees particularly are working as we speak on Medicare, and I think that's going to be a factor, at least in terms of the prospects for the year.

So in terms of looking at the outlook for the legislation in the House, I'd say that particularly given that we're supposed to be done by November 7th, and I continue to say that because I hope we are -- I don't know if we will be but that's the target adjournment -- that leaves us two legislative weeks with about two legislative days, because I think they're in about one or two days each week. So that means that this is not an issue for this year. Certainly staff will be spending a great deal of time and are already spending a great deal of time looking at the bill and looking at the issues surrounding the bill and evaluating it and hearing the statements from various parties who are interested in it from a variety of different perspectives, and I think that's what we'll spend the majority of our time doing this year.

And then I think during the following year folks are still making decisions about how this will proceed. Certainly it's something that I think will go in a regular order process, meaning that we'll spend the time to do the hearings and the kinds of things that are necessary to inform the Congressional members about the issue and that kind of thing. I think that will determine how the House proceeds and what the perspectives will be for the coming year on the issue.

So I think that's kind of my view for the House perspective, but I'm happy to answer anybody's questions about the bill or thoughts about it.

DR. McCABE: Well, thank you very much for taking time out of your very busy schedule. Now we hear how busy it is than we even appreciated before this. We also know that the spotlight is on the House with the unanimous passage in the Senate, but we really do appreciate you coming.