2014-10-22 Karen Rothenburg

So, I'm from New York, as you can probably tell, although I've lived in Washington since I got out of graduate school in 1974. I have an education of both an undergraduate degree and a graduate degree in public policy from the Woodrow Wilson School at Princeton. I graduated in the first class of women, so it was a very interesting time to be there, and I was in a special program where I could do my undergraduate and my graduate school together. So I actually skipped a year of college. In four years, I did six years of education.

I got out of graduate school. I was 21 years old, and I moved to Washington, D.C. At the time, I wasn't sure I would go to law school. My father was a lawyer. I was probably thinking more of getting a PhD in public policy. I had an incredible opportunity at Princeton to work with Uwe Reinhardt, who is probably the most innovative health economist, I think, in the world, and it was wonderful working with him. It was at the time when we were just thinking about using health maintenance organizations, and when we were looking -- not for the first time, but for one of the first five times, perhaps, of thinking maybe we would get national health insurance. And the Nixon Plan at the time -- this was in the early 1970s -- was probably more liberal than what we ultimately ended up with. But I got very interested in looking at alternative healthcare systems, and that's why I came down to Washington: to work for a consumer owned and operated HMO.

My interest in health goes back to -- was trying to think, growing up as a little kid, there was no way I was going to be a doctor, but I was always interested in health. My father got sick at a very young age, and maybe that had something to do with it. I really don't know. It was exciting times. But by the time I went to college, I knew I was interested in combining health policy together with economics and sociology, and history, and you could do that by being in the Woodrow Wilson School. So that was where I wanted to go, and I was lucky enough to get in.

I actually worked for a few years in Washington, D.C., and decided after working for a few years that I needed to change the health care system, but I was not going to do it as a doctor. I just was too afraid of the sight of blood.

So I figured rather than getting a PhD, I might be better off with a law degree, mainly because I thought, well, doctors are afraid of lawyers, and maybe they'd listen to us. I don't know. But I thought I would change the health care system using law. And so I didn't want to give up my job because it was at the time that they just passed the law for federal recognition of HMOs, and the one I was at was one of the first to get qualified, so I was responsible for working on that. So I was doing that, and going to law school at night at Georgetown. And then my husband, who was finishing up law school, decided he wanted to get a PhD in clinical psychologies.

So we needed to find a place where we could both do that, and we were able to do that at UVA. And UVA had one of the first professors teaching health law. It wasn't really a discipline back then in the 70s. By this, it was the late -- mid to late 70s. There -- it was just an evolving discipline that mostly had to do with mental health issues. But his name was Walter Wadlington, and he actually wrote one of the first case books in the area, and I thought, “This is really

interesting. This would be a way I could combine my law and my health interests," and that's what I did.

What was your experience like studying health law? How did it launch your career?

Well, when I went to law school, there were still very few women, and UVA is a southern, conservative place. I was really a little bit out of step there, I think, but I had a really, really good education. It was also a place that Jeff and I fell in love with being outside. I mean, we got to do -- go into the mountains a lot, and spend a lot of time in nature, and the pace of the place was really nice. And it turns out both of my daughters landed up going to UVA for undergraduate school, in spite of my best efforts to get them interested in Princeton. So we must have expressed a lot of love for the place, and we went back down there a lot, you know, when they were little, so it was -- we have very fond memories of being there.

We ended up only having to be there for two years, because Jeff was able to -- he got his -- all but his dissertation done, and his practicum, and they were able to count his law as his minor. And I had done a year and some summer work down at Georgetown, so we were able to just be there for two years. And then, I made the decision not to do a clerkship at the time, because I thought I was so old. I don't even think I was 30 years old. But I then was able to get this fantastic job at Covington and Burling, which is in Washington, D.C., in a very unique practice, because I didn't see myself as corporate law material. I thought I would go work for the government, because it was a very exciting time to be working on health policy. But they had a practice where they represented state welfare and health organizations that were either trying to get more money from the federal government, or fighting private industry in their particular states, so it was a fascinating practice, and that's what I did. And I had great mentors, and in my first year, I was working on a problem that landed up going to the Supreme Court. So it was just a very exciting number of years.

How did you come to the University of Maryland Law School?

While working there, one day, the phone rang, and it was the University of Maryland, interested in whether I would want to think about going into academics.

So, you know, I guess I'd like to say I had this plan all, you know, this path all clearly made for me, but it wasn't. It was this phone call. And at the time, I had a little baby, and I had taken a wonderful opportunity that Covington offered to go work at a legal services office for six months. I could take my paralegal and my secretary with us, and get paid my Covington salary, and it was while I was doing that that I got the call from Maryland.

So I -- the rest is history. I went to -- I didn't look at any other law schools, I went to Maryland, and when I was in the office, talking to the dean at the law school, I looked outside, and I saw all these health professional schools were on the campus with the law school, and I said to the dean, "Well, if I came here, would I be able to do something with these other schools?" And he said, "Of course." And I innocently didn't realize, well, that was on top of teaching four courses, and then soon having another baby on the way.

How did you start the Law and Healthcare Program at the University of Maryland Law School?

That's where we started the law and healthcare program at the law school, which I'm proud to say is now ranked number one in the country.

And the goal of the law and healthcare program was to bring together law students and medical students, social work students, nursing students, pharmacy students, dental students, so we could really think about looking at health policy in an interdisciplinary way. And that's what we did at the law and healthcare program, and we still do. It's very focused on how do you use law as a tool to make an improved policy? And Maryland's unique because it's the state that has all the regulatory agencies -- are in Maryland. So it's just like such a natural fit for us.

How did you become involved with NIH in the early 1990's

I made the decision that when I could have my sabbaticals or leaves from the law school, I would do them here. So I think it was always with me that it's not only good -- it's not good enough to just teach about it. You have to do it. You have to recognize that you can write all you want, all these law review articles and interdisciplinary articles about how things should be, but if you can't work in the institution and try to make it happen, then you're only telling part of the story.

So I arranged at my first sabbatical to come here. I had been on a number of committees over the year. I think my experience oat the Woodrow Wilson School, I had met some people that had done mid-career sabbaticals where they could come to the Woodrow Wilson School that I had met, and we regrouped after I got back to teach. And even when I was at Covington, I was involved in doing a lot of pro bono work. I realized I needed to be not only an academic. That wasn't going to keep me satisfied.

And so I did a lot of work with the nurse midwives. My interest was actually initially in women's health, and then it turned out in the beginning of the '90s, women's health was merging with genetics because the area where there was going to be the most focus in genetics was prenatally, and I had personal experiences with this that actually informed my scholarship, which I'll get to in a minute. So I arranged that I would work at NICHD. There wasn't really a genome institute, or an ELSI Program, yet, so -- but at NICHD, the head of the policy office was somebody I had known from the Woodrow Wilson School. So he had come mid-career to the Woodrow Wilson School, and I was in graduate school, and we worked together. And so, then, he must have remembered me. Over the years, he was asking me to work with them on various projects. So then, when I had the sabbatical, it was a natural. I had gotten to know the director of NICHD, Duane Alexander at the time, and, in fact, I ultimately served on their council. So I did a lot of work with NICHD.

So I was at NICHD, and down the hall from me was somebody else on her sabbatical, and that was Elizabeth Thompson.

Can you tell us about working with Elizabeth Thompson?

The ELSI Program was still just beginning to evolve at that point. She was working at NICHD, like I was, on sabbaticals, but evolving was the genome work. So -- and she had this genetic counseling background. So she then got pulled in as Eric Juengst came to really be working with them, and then she ultimately got moved over to work with the Genome Institute. I don't even think it was an institute, then, but in helping to evolve the ELSI Research Program. And early on, there was a need from a number of the institutes to say, "Well, look, we could do genetic testing for this particular gene. What will it mean?" And they did not have any set asides, or expertise on looking at the ethical, legal, and social implications, like the Genome Institute, or -- I think at the point it was a center, at that point.

So some of the first interests was looking at things like the breast cancer gene, as BRCA 1 and 2 research was being done, and then that became just such a natural for me -- I had already gone back to teaching-- because for me, it merged together my interest in women's health and genetics in the non-prenatal area, although, of course, now that's come full circle, too, and that was just a natural, for when I left, to continue to work with her.

So once we met in '91, then we put the conference together, then we had the series of papers on fetal therapy, and then we got the book contract to do the book.

What was Elizabeth Thompson's legacy?

She was a force of nature, and, you know, she came from Iowa. She's so principled. You know, Elizabeth is not a big compromiser. You know? She feels very strongly about what she feels strongly about, and sometimes, that makes people uncomfortable, and sometimes it makes people really proud of her. And she's a doer. She was really a doer. And I think the model that we still have today, the successful model for the consortiums that now is just matter-of-fact.

You know, back in the '90s, when we put together the Consortium for Cancer, for the breast cancer work. That was a model to me of how you make policy. It was brilliant. And she was really behind that. Carefully choosing who's going to be sitting around the table works for consensus as well, but, you know, tons of scholarship coming out of that, really -- very well-done policies, always being, I think, probably, a thorn in the side of the scientific community, like, thinking about the ethics of the way things were being done. That was Elizabeth.

How did growing up in Cold Spring Harbor influence your work?

I grew up in Cold Spring Harbor, Long Island. I grew up amidst anti-Semitism, and, you know, the genetic inferiority of certain groups, and that's where it started. I mean, I was not knowing when I was growing up. It was hidden, but it was where the whole eugenics movement in this country evolved. In my town. I used to drive -- in high school, I worked in the labs. I used to drive up and down that street named after Davenport. I mean, he was just such a eugenicist. So, I guess I had an extra level of sensitivity about it.

Why did you start working with Jewish communities?

You know, what I saw evolving was that we started to call things "Jewish genes." Like, that there was some connection between our ethnicity, and our religion, and our genetic mutations.

And I remember an interview on NPR saying "My mother had said to me, what is it about us? Why do we have all these bad genes?" You know, which was just fitting right into what this perception was that I was seeing happening. And there was arguments going on in the American Jewish Congress, and my position about that -- knowledge is power, and that we all need to be supportive as a community of more and more research being done here, and this would be good for our community. So we were on a collision course that if we start to study these mutations in our community, it was just going to exacerbate the level of discrimination and stigma. On the other hand, it was power.

What caused the most concern?

The closer you got along a continuum from cancer and heart disease to behavioral genetics, the more fears you'd see in your community. But when it came to something like alcoholism, the Jewish community wasn't really worried about stigma. But if you asked those same questions to the Native American community or the Irish community, they might be. So the level of support and comfort could have to do with the stigma associated with stereotypes in your community.

How did you first meet Frances Collins? What was your impression of him?

So I must have met him in his -- first in his official capacity pretty early on. Either I was on a committee -- I was asked to be on a committee, and I was doing something with the Genome Institute. I was working with the ELSI Research Program, really, from the beginning, but I was not on the initial working group. I just got, I think, involved by getting to know Eric, and getting to know Elizabeth, and then knowing they could depend on me. And I wasn't asking -- they weren't having to fund me. You know. I just was in an area of public service that I was doing.

So I got to know him pretty early, and then it became clear we had these common interests. Like, his mother was a playwright, and I love the theater, and he loved his -- playing his guitar, and we just had a lot of common interests, and I could tell it was just -- more than just feeling like, "Oh, she could do the work if I asked her." You know? I think he respected my opinion, and he -- I don't want to say he took advantage of it. He involved me in a lot of policy discussions, and decisions, and committees, and the same with Kathy. I mean, we did a lot of work together, and, you know, working with Kathy was working with Francis.

Do you think the rules on the Genetic Information and Nondiscrimination Act will be revised?

You could see that there might be compromises, or moratoriums like we've had in other countries, where, like, you know up to 250,000 or up to 500,000 of certain kinds of insurance, you can't ask any of these questions. And then, you know, you want to get up into those higher levels, you can. So -- but there are other mechanisms that you can save for besides life insurance. If you've got -- I mean, it's an upper middle class, high class issue to begin with, as to

whether or not -- who's buying this insurance? I mean, who can even afford disability insurance?

So -- but will we revisit it? Well, probably not any time soon, because it's not that high a priority. And, you know, like, in the scheme of the world, I think, you know, we're the Genome Institute. But in the larger world, I don't think it's that big a priority to be worrying about this area.

What will the future of privacy look like?

I mean, I think people's expectations of privacy are really complicated, because post-9/11, we don't have really any expectations of privacy when it means that we're not going to have a terrorist destroy us, but we still hold on to some sort of privacy, even with Facebook. And, you know, all these things, when it comes to our health.

Now, maybe your generation feels differently about that than my generation, but we still hold on to that, and that could change. Now, whether that translates into sharing, which I think is the bigger issue, when we get to a point in our society where we recognize that we need to share our data for the betterment of all of us. And I think that's something that some countries have gotten closer to than others. You know, I don't know where democracies fall in there, but also, if you want to buy into that, then you've got to work at not having health disparities. You have to be able to show the connection between those. We're not there.

[end of transcript]