



Oral History of the
Belmont Report and the
National Commission for the Protection of Human Subjects
of Biomedical and Behavioral Research

Interview with
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INTERVIEW

Interviewer: LeRoy B. Walters, Ph.D., Professor of Christian Ethics and Professor of Philosophy, Kennedy Institute of Ethics, Georgetown University.

MS. LEBACQZ: I am Karen Lebacqz. I was a Commissioner on a National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. I am Robert Gordon Sproul Professor of Theological Ethics Emeritus now, at Pacific School of Religion in the Graduate Theological Union.

INTERVIEWER: It's been some time since the Belmont Conference and you and I both had the privilege of being at the Belmont Retreat Center for that conference. It's hard to remember a lot of details, but I'm wondering whether you recall how we came to the idea of three principles of beneficence justice in respect for persons?

MS. LEBACQZ: I don't remember this specific conference as well as I remember the work that led up to it. And, I think, my memory would be, that these three principles emerged out of our ongoing work. That when we struggled with research on children, we looked carefully at issues around beneficence and non-maleficence.

When we struggled with research on prisoners. One of the big issues that emerged was about justice and how you can take a vulnerable population, such as prisoners, and ensure that they are treated fairly given the total institution in which they reside. So, I think the three principles came in part out of the kinds of issues that we had been struggling with as we looked at research on the fetus, research on children, research on prisoners and the other specific populations. Do you mind if I just sort of take off on some of these questions?

INTERVIEWER: No, I don't.

MS. LEBACQZ: Okay.

INTERVIEWER: One of the three Belmont's principles is respect for persons. And, I believe that you Al Johnson may have had something to do with the inclusion of that principle. Could you say a bit more about your work on respect for persons.

MS. LEBACQZ: In my way of thinking, the principle of respect for persons is absolutely crucial. And, it is the number one principle. And, it needs to be framed in the language of respect for persons. My memory is that we did struggle at Belmont over what to name this principle. And, I suspect that it was Al Johnson, and perhaps several others and I, who argued that we should use the language respect for persons.

Part of the reason for that is that we had a history of some research that was very disrespectful of persons. The Tuskegee Syphilis Study, some of the early work that had been done on birth control using women from other countries who were never given an opportunity to consent. Did not know that they were participating in research. So, we wanted a principle that would require that people be from the outset, respectful of all the subjects who would be participating in research. In subsequent years the principle respect for persons became in the work of Beauchamp and Childress. Their very famous book on principles for biomedical ethics. That principal became a principal of respect for autonomy. And, it's my personal view that that is unfortunate. That respect for persons is broader than respect for autonomy.

Autonomy, the capacity to make ones own decisions is surely an important part of what it means to be a person. But, it is not the only part. Children are persons even though they are not autonomous. So, the principle of respect for persons needs to include dimensions outside of autonomy. And, I would argue for the integrity of the language that the National Commission used, and I think it is the better language.

INTERVIEWER: There was a book published in 1970 called, Respect for Persons, by Downey and Telfer. Did you use that book in your own teaching or had you read that book as you entered into the Commission Deliberations?

MS. LEBACQZ: Yes, Al Johnson and I had teamed taught a course in ethical theory. And, we used Downey and Telfer's book, Respect for Persons, as one of the text for that class. The book is really an effort to spell out what a continuum perspective on ethics requires. And, it is quite strong on an understanding of what respect for persons means. And, in my view, sees that as going beyond simple respect for autonomy. Though many people do take comps ethics to be rooted in the concept of autonomy.

INTERVIEWER: The Commission came up with three principles and you've now had more than 25 years to think about whether three is the right number. Can you think of other principles that you would like to add to the three in light of your thinking in the mean time?

MS. LEBACQZ: If I could go back and do it over again, would I do some things differently? Probably. Though, I think what we did at the time was good for its time. Would I add principles? I don't know if I would add principles so much as I would try to spell out better than we did the inner meaning of the three principles that we had.

For example, I really do believe that respect for persons needs to include a kind of subprincipal of respect for a persons community, respect for the embeddedness of people in their cultures, and so there are ways of getting respect for culture into the principle of respect

for persons. That's one that I would like to see either added or at least elaborated.

Similarly, we talked about justice and we talked about it primarily in the language of equal treatment and protection of the vulnerable. A language that we did not use in those days but that that has become very prominent since and very important to me, is the language of oppression. I think there is a difference between populations who are simply vulnerable and populations who are oppressed. And, justice requires rectification of oppression and that might set some structures differently than the way that we did so many years ago.

So, if I were doing it over again, I would not deny any of the principles that we used, but I would want them extended and expanded. And, I might have additional principles that I would want to lift up as well. I believe that human life is relational at its core. And, perhaps a principle of covenant or promise keeping would also have been an important part of respect for persons, or maybe even an additional principle.

INTERVIEWER: In your own work since your time on the National Commission, the principle of justice has played a very prominent role. Justice between genders, justice in ones ethnic groups, justice between the first world and the third world, are the ways in which you would like to see then the notion of justice enriched.

MS. LEBACQZ: Absolutely. When the Commission did its work, I think we were perhaps on the forefront of identifying justice as an important principle. But, even in the Belmont meetings and in our struggles with the Belmont document, we were never able to spell out fully what justice would require. A good bit of my own work since then has been grappling with this difficult principle of justice and trying to determine what it does require.

And, as I've already indicated, I would see a crucial question today as the question of oppression. In part of what was so disturbing about the Tuskegee Syphilis Study is that it was not only a study that was done without the informed consent of people, that alone would be bad enough, but it was a study that was done on an oppressed group of people who were taken advantage of because of their oppression. And, that kind of exploitation is absolutely anathema.

So, justice requires not simply treating people equally, we could treat everybody equally and still be oppressing all of them. Justice requires attention to power issues, how to redress the power in balances in life. Some of my own work on justice has involved looking at what it means to acknowledge that we have made mistakes, or done things that are wrong, and that we need to rectify those. What is reparative justice, for example.

So, from my perspective, the Commission really did a great service to the field of bioethics by lifting up the principle of justice. But, we did not give a full enough account of what justice

would require. And, there is a great deal more work that needs to be done on that.

INTERVIEWER: Well, let's move from Belmont back to the beginning in the early months of the Commission's work. The fetal research topic was the first one on the agenda. How did you experience your work with the Commission beginning with the first meeting? I mean, what was it like to come into the room with this group of people, and you probably only knew a few of the people in the room, and how did you experience the work on the fetal research report?

MS. LEBACQZ: I was very young and very naive, and I honestly did not know what I was getting into when I agreed to serve on this Commission. My memory of those first months was feeling overwhelmed by the enormity of the task that we had been set. Very grateful for the wisdom of the group in choosing Ken Ryan to be our chair. And, enormously grateful to the Commissioners as a whole for the respect that they had for each other and for me as very young and relatively unseasoned person in the field of ethics.

I have several early memories that are very strong. One was how difficult it was for us to talk to each other in those first meetings. We were giving four months in which to come to a conclusion on what has to be one of the most difficult topics ever. It remains a controversial topic with a current controversy around stem cell research. In those days it was not stem cells but research on embryos and fetus's. Certainly one of the most controversial and divisive of our topics.

And, I remember that it took us almost four months to develop a common language so that when the scientist talked, the rest of us understood what they were saying. And, when the lawyers, talked the ethicist understood what they were saying. And, I still remember that Al Johnson and I as the ethicist on the Commission would say something on the order of, that's not a morally relevant difference.

And, after about three months of this, I forget who it was, but I think maybe one of the scientist, finally thumped his fist down on the table and said, you keep using this phrase, morally relevant, and I don't know what it means.

So, just finding a common language and being able to understand each other at the beginning was very difficult. We were diverse in terms of our academic fields. While most of us were academicians, and in that sense, maybe not very diverse, we were certainly diverse politically and in terms of our faith, traditions, and our convictions about the fetus and the standing of the fetus.

So, trying to come to common ground was not easy in those early months. I do remember one of my strongest memories of the Commissions work overall, was how quickly Pat King, who was one of our lawyers on the Commission, Pat King and I would hear a comment and

both of our hands would go up at the same time. And, Ken would call on one or the other of us. And, we would look at each other as if to say, do you want to answer this one or shall I answer this one.

And, so often we were trying to make the same point in spite of the fact that her legal language and my language coming out of the field of ethics were slightly different. So, I really felt early on that I had a good colleague in Pat King. That she understood what I was trying to say, and that if I had difficulty getting others to hear it, she was able to step in and say it again in a different language that maybe others could really appreciate it.

So, I have memories of both the difficulty of coming to common ground and the difficulty of talking with each other. But, also of the great respect of Commissioners for each other, of our efforts to assist each other, and particularly for me, having come into it relatively unseasoned, a tremendous gratitude to my fellow Commissioner's for the respect that they showed to me.

INTERVIEWER: Do you feel a sense of general satisfaction about the fetal research report when you look back on it even though it had to be put together so quickly?

MS. LEBACQZ: It was our first report and it was not, I don't believe, our most controversial report interestingly enough. One of the things that we did that made a difference to our work was to bring in a number of scientist very quickly to talk to us about fetal development. So, that we were trying to do our ethical work based on as careful scientific knowledge as we could attain as lay people. So, I think that set an important precedent for the work that we did overall.

Am I satisfied with the report? Given the constraints under which we worked, I would say yes. Would I do some things differently today, yes. I think we know some things today perhaps we did not know then. I have since learned, for example, about the zona pellucida which I did not understand or know anything about in those days.

The question of whether that very early embryo is simply a collection of cells being held together in a kind of sac if you will, or whether it is already an integrated organism. That could make a significant difference for how one goes about doing ethics for early embryos. And, I did not know anything about that in those days.

So, perhaps I would do some things differently. But, overall I was pleased that given our differences on the Commission, given the constraints of time and the difficulty of learning a common language, we were able to come to a report that was amazingly united I think under the constraints.

INTERVIEWER: How important do you think it was that the Secretary at that time of

Health, Education and Welfare had to respond in some way within a 180 days after a report and recommendations were submitted?

MS. LEBACQZ: Terribly important. Subsequent commissions or counsels on bioethics have often been simply advisory. And, the problem with being an advisory, Bobby, is nobody has to take your advice. You can promulgate good ideas, but if there is no structure that requires that they be taken seriously, they can simply be ignored.

The difference in part for the National Commission on which I had the privilege to serve, was this law that brought us into being that required that what we proposed had to become rules and regulations unless there was good reason not to promulgate it. The Secretary of then DHEW was given a specified amount of time in which to publish our recommendations and seek responses. And, then if the Secretary departed from what we recommended, the Secretary had to explain why.

So, throughout the process there was a kind of bite about our recommendations. They either had to be turned into law, or there had to be good reason that they weren't turned into law. And, those reasons had to be communicated publicly in a way that was widely accessible to everyone. And, I think the public reasoning process was terribly important part of our process, both in terms of how we went about trying to formulate our recommendations, and also in terms of what then happened with the recommendations.

INTERVIEWER: As you look at all of the reports that the Commission produced, is there one or are there two that stand out in your mind as the best work that you ever did?

MS. LEBACQZ: I think my favorite of all the Commission's Reports would have to be the report on prisoners. First of all it was for me, a tremendously important learning experience. The Commission went into a number of prisons. We went into minimum security and maximum security prisons. And, it was, I confess, the first time that I had ever set foot inside a prison. We interviewed prisoners. We heard their stories. We saw the research quarters where research was being done on prisoners.

And, on one occasion we went to Jackson State Prison, which is maximum security, and the Commission was absolutely determined that we would be able to hear from prisoners without them being put at any risk. So, we insisted that it be only these prisoners, who most of whom were in for murder. They were either life long prisoners, or had many, many years to go before they would be paroled. We insisted that in the room there would be only the prisoners and the members of the National Commission. No guards allowed in the room.

I'm amazed in retrospect that we were able to accomplish this. But, I will tell you truthfully, it was one of my most life changing experiences. As I sat and heard prisoners talk to us about

their stories, why they were there, they admitted freely they had murdered someone, or done armed robbery, or whatever it was that had brought them there. And, then we talked with them about the research unit. It was the only time in that entire day that I felt safe.

The rest of the time we walked around the prison grounds with guards with guns trained on us. The only time all day that I felt safe was when I was outnumbered by a whole bunch of convicted murderers and hard-timed felons. I had day mares, not just nightmares, but day mares for months afterward. Visions would come back to me of how horrible the conditions were for the prisoners there.

So, we were determined that these people who live in a total institution where they have very little control over anything, should be treated with great respect if they are to be subjects of research. Many people thought we should simply ban all research in prisons. But, the prisoners themselves said, the research unit is the best place to be in the prison, that's the place where we get treated as though we are human beings.

So, instead of banning research, what we tried to do was set requirements so that in order for research to be done in a prison, there could not be such terrible conditions in the prison that being part of the research project became what we called an undue inducement. If it's that much better in the research unit, then prisoners will want to get into it no matter what the risk of the research might be.

So, we tried to not only keep the risks minimal, but also make sure that the conditions in the prison itself would be such that there would not be undue inducement for people to participate in research. I think that was one of our most important recommendations.

The understanding that coercion is not just about somebody holding a knife to you and saying you have to do this, but there can be something coercive about making an environment so good compared to what the person normally lives in, that they really cannot easily make an informed decision about what they're doing.

So, for me the report on prisoners, is my favorite of our reports because of the ground that I think we broke in that report, but also because of the experiences that we had in order to do the report. And, I could talk for hours about those memories for me are very, very strong memories. Everyone of the prisons that we visited I can walk right back into the corridors in that prison in my mind those memories are so strong.

INTERVIEWER: It's ironic that the recommendations of the report on research involving prisoners were never translated into regulations. That's a loop hole in the current oversight system. Are you disappointed that that didn't happen?

MS. LEBACQZ: Yes, very. And shortly after the National Commission had come to a close, several of us were invited to go to a prison on behalf of a drug company that was doing some research there. We were invited to go and tell them whether we thought they could ethically conduct their research.

Quite frankly, if the recommendations on prisoners had been promulgated, it would have been very clear that they could not do the research that they were doing. Not because the drug company was doing anything wrong. Its research was very low risk, but the conditions in the prison did not meet the minimum standards that we had laid out so clearly in our report.

INTERVIEWER: Research involving children continues to be a very important and much discussed issue. As you look back on the report about research involving children, what do you see as its strength and weaknesses?

MS. LEBACQZ: I said earlier that ironically I did not think the report on research on the fetus was our most controversial topic. I think our most controversial topic was the report on research on children. We had the most difficulty in some ways coming to agreement on that report.

And, so, one of the things that we did there and elsewhere was to reach a point where we said, we are not going to agree on this. Let's make sure that minority voices can be heard. And, to put out a report that included the majority report and then several different minority voices.

But, of the things that we did within the report that are important, I think for me the notion that children beyond a certain age need to assent to research even if they are not old enough to give an informed consent. Saying, if they are old enough to understand that they are participating in research, and why they are being asked to do that, then they should have to assent to it. They should have some right of refusal.

For me, that would be another part of the respect for persons. Children are not autonomous. They can't give a fully informed consent, but they should be respected enough to be given the chance to say, no, not necessarily to medical treatment. But, when you're talking about research, you're not talking about medical treatment, per se. You're talking about the kinds of things that are done in order to allow us to gather data. And, I think children beyond a certain age should have the right to say no to that.

INTERVIEWER: Let's look at the other side of the picture and that is which of the reports was the most disappointing to you, or where do you feel the Commission did the least thorough job?

MS. LEBACQZ: One of the places where I think in general we were weak, was that our model for almost all of our work was biomedical research. We were a Commission that was supposed to look at both biomedical and behavioral research. But, through almost all of our reports, we used the biomedical model as our primary model.

So, I would say that we were weak at the point of really looking at some of the very important kinds of issues that come up when you do behavioral research, or when you're simply interviewing human subjects about things. Are there particular vulnerabilities for people who come out of populations that don't have a concept or a history of informed consent.

For example, I have subsequently served on the Human Subjects Committee at the University of California Berkeley main campus. Most of the research that is done on that campus does not involve any biomedical interventions. It is largely faculty and graduate students who want to interview people or set up focus groups for discussion about issues such as drug use or whatnot.

When you ask people to talk about their drug use, and you are in fact asking them to share information that could potentially put them at risk, we really did not deal with a number of those kinds of issues. And, I think there are still significant questions like that for which much more ethical analysis is probably needed.

INTERVIEWER: Did you feel that right from the start the Commission was totally independent of influence by NIH or the Department of Health Education and Welfare, or do you feel that as if the Commissioners and the staff had to fight for your independence early on and establish your independence?

MS. LEBACQZ: For the most part I think that from the very beginning we were quite independent. I do remember at several early meetings where staff had taken some of our discussion and attempted to develop rules and regulations or to develop a report based on the discussion. And, they brought it back to us and we got angry and said, you are promulgating your own ideas. You are not reflecting the conversation of the Commissioner's.

So, I think very early on, although in general we were very grateful to our staff, relied on them heavily, and thought they were wonderful overall. I think very early on we established a pattern of saying, the work that gets done here will be the work of these Commissioner's, not the work of anybody else.

And, we resisted any suggestion that we needed to capitulate to what current practices were in any of the government departments. We really saw ourselves as having been given a

charge and a commission and taking responsibility for trying to do that charge and that commission.

INTERVIEWER: As I recall there was even somewhat of a change in the staff in those early years, precisely in order to achieve greater independence, for example, from NIH influence.

MS. LEBACQZ: Yes, that is true. And, we were lucky always to have some folks from NIH or other departments of the government who came and sat through our meetings as observers. And, were sometimes very helpful to us behind the scenes, giving us reflections on what they had observed as they listened to us.

But, they were, I'm thinking for example, of Natalie Redick, who at that time was in the Office for Protection from Research Risk, I believe it was called at that time. Who came, I believe, to every single one of our meetings. And, was a very thoughtful observer, but did not attempt to intrude or to sway the voices of Commissioner's.

We would have been a hard group to sway. We argued enough with each other that there wasn't a whole lot of time for other people to have a whole lot in put. Except for the times when we deliberately set up for public in put and we did hold public hearings, and we asked some pretty tough questions of the people who came and testified before us.

I still remember one man on his way out looking at me and saying, you're a lawyer, aren't you? And, he didn't quite believe it when I said, no, I'm not. I think it was because of the kinds of questions that we put to everybody.

INTERVIEWER: The Commission met often once a month and then the staff was working in between the meetings, but after your recommendations went forward, there had to be some people in the trenches in the federal government who would translate your recommendations into regulations.

I'm thinking, for example, of Charles McCarthy, in the Office for Protection From Research Risk. And, I guess my question is, how important do you think it was that there were long term government officials there who did their level best to translate your recommendations into new regulations?

MS. LEBACQZ: It was probably more important than I realized at the time. At the time, I would have to say that I was so focused on the enormous task that had been set before the Commission itself, that I did not pay as much attention as perhaps I should have to the hard work that went on behind the scenes from people who had to take our ideas and turn them into the kinds of rules and regulations that lay things out clearly enough for IRB's to be able to follow what is being required.

Certainly, I think all of us felt a debt to people like, Charles McCarthy, who did that kind of work. But, at the time I was always focused on the task that we had been given because they were so enormous. We met once a month. I used to call it my 48 hour red eye special. Would fly from California, usually overnight after teaching all day, sit through two days of meetings, and then got on an airplane and fly back to California arriving back late on the second day.

I started drinking coffee when I was a member of the National Commission. I had never drunk coffee before in my life. Not even when I was in college. But, by mid-afternoon on the second day I would be so tired that I finally turned to caffeine to keep myself awake because all of us were doing it as an extra job over and above a full time teaching job. At least I was never given any time off for the work that I did with the Commission.

We met for a formal meeting once a month. But, when we were doing our reports on different population groups, such as people who were institutionalized in mental institutions, or prisoners or children, we also did a number of field trips. And, there were many months that I was on the road two weekends out of the month doing the work of the National Commission, either the official meeting or the site visit.

So, it was very, very demanding and my energy was going into reading all the background materials that we collected. All the experts who wrote papers for us on different topics to try to help educate us about the kinds of research that were being done on children, for example.

INTERVIEWER: At that time there was not electronic mail and I don't think there were even fax machines. So, I guess all of the work of the National Commission had to be done through mailings of paper documents, is that correct?

MS. LEBACQZ: Huge dockets we would receive every month before the meeting. Usually a-- a few days before the meeting we would receive a huge packet of materials. It might be as much as a 100 or even 200 pages. We were expected to read all of it.

Fortunately for me, the plane trip from California back to Washington, D.C. was usually about a six hour flight. And, I would get on the plane and read non stop until I got to the other end. So, yes, you are right. I certainly had no email and no fax machine in those days. And, our work was conducted by what we now call snail mail. And, there was a lot of material to digest in between meetings. And, then it was hard on the staff as well because they met with us over a weekend. So, normally the days that they were supposed to have off, they would need to be working.

And, then in theory they should take several days off to make up for that time, but in

practice, if they were going to take what we did, and turn it around, and get a draft back to us so that we would have a week to read it and digest it before returning for the next meeting, they pretty much just had to turn around and keep working non stop. It was non-stop hard work for all of us those four years of the life of the National Commission.

INTERVIEWER: In terms of your own academic career, would you say that your work on the National Commission set an agenda for your work subsequent to going off the Commission, or did you move onto other topics since that time that sort of complement the focus of the Commission?

MS. LEBACQZ: The National Commission really did two things for my career. First, because I was very young and not well known in the field of bioethics, serving on that Commission catapulted me into the public eye very quickly in a way that I think otherwise would have probably taken at least ten years for me to achieve.

And, it also gave me connections with people in medical schools and universities that I might not otherwise have had as I have spent my entire professional career with just a couple of exceptions, several leaves of absence, but the bulk of my teaching has been at a small religiously oriented school that would not normally be the venue from which you would think someone does bioethics.

So, serving on the Commission was a tremendous boost to my career and to giving me a public presence that I might not otherwise have had. With regard to the subject matter, I would say that for a few years after the National Commission, I continued to be very active in doing work on ethical issues around human subjects research.

But, one of the things that happened to me after the promulgation of both the Belmont Report, and especially the Beauchamp-Childress Volume on Principles for Biomedical Ethics, is that the field of bioethics seemed to me to become captured by this idea that there are a few basic principles and that the way to do bioethics is to take any subject matter or any case study and simply take these principles and apply it.

After about ten years, I became quite disillusioned with that approach to the field of bioethics. And, I withdrew from that field a bit. I was, after all, teaching in a school where most of my students are going on either to be clergy, or to teach in the field of religious studies, and so I began to do a lot of work on clergy ethics and on professional ethics more broadly. Not losing the importance of the principles and the work of the Commission, but shifting direction a little bit into a different field.

I finally came back with some energy into the field of bioethics when I saw that the field itself had begun to expand the ways that we do bioethics, and not simply be captured by

principles, but begin to look at ethnography and the importance of trying to understand a community from the inside out in order to ask what is ethically acceptable for that community, or look at virtue theory. So, that we look not simply at what we should do, but ask questions about who we are supposed to be.

So, with the expansion of the field of bioethics that really began in the mid to late 1980's, I began to feel that there was room in the field for some new and creative endeavors, and particularly, with the Human Genome Project and the importance of some issues in genetics, I moved back into the field of bioethics and put more of my energy back in that field.

INTERVIEWER: Would you say that you've always been a feminist theologian, or a feminist ethicist, that you were a feminist at the time of your work on the Commission and you've continued that accent in your work?

MS. LEBACQZ: I remember the precise day that I became a feminist. It involved a xerox machine at which I was standing doing some xeroxing of materials for my class. And, one of the trustee's of my institution came in, saw me standing there, presumed based on my gender that I was a secretary, and handed me a stack of things with the request that I xerox them. That got me to thinking about stereotypes and how we pigeon-hole people and presumptions are made about women and who we are in the world.

So, I would say yes, I was a feminist from early on from the early 1970's and certainly before the time of the National Commission. I do think, however, that the work of the Commission does not reflect a particularly feminist vent. For example, partly because it was not in the law that brought us into being, but perhaps partly a fault to be laid at the feet of the Commission.

We never stopped to ask whether women were a particularly vulnerable population. Whether there needed to be any special rules or regulations for research on women. So, although I was a feminist and I am fairly sure that Pat King was a feminist at that point, partly because there were only three women on the Commission, and I would say that our colleagues by and large were not at that time feminist.

Though, I think many of them may have become since that time, I hope so, but partly because of that and partly because of the specific tasks that were laid before us in law. We did not focus on some issues that I would today hope that we focus on taking a feminist perspective on research on human subjects.

INTERVIEWER: And, final question, since the National Commission there have been several other Commissions and Boards that have had similar roles. There's currently a President's Counsel on Bioethics. I wonder if you would mind comparing the work of this early Commission with the work of subsequent groups.

MS. LEBACQZ: My feeling is that the National Commission so many years ago was important and successful in a way that subsequent Commissions have not quite managed to be. And, I'm not sure why. I wish I knew. It may be partly because the law that brought us into being did require that our recommendations be promulgated, or if not, good reasons be given for why not. Whereas other Commissions have been advisory and published their reports, but the reports did not have any bite built into them.

It may be partly attribute to Ken Ryan who was a superb chair. Who, very early on, I think, made some very wise decisions about how to get public input into the work of the Commission without that public input obstructing the work of the Commission. It may have been that we were, at that time, naive, all of us, we were new at this game, there had not been other Commissions. And, so we just did our work as carefully and seriously as we could. And, we weren't so captured by some of the politicization that I think has happened since then.

I think it is truly a tragedy that the most recent President's Council on Bioethics lost two members whose terms expired and they were not renewed. And, there is at least some evidence that that was a deliberate political decision because of the positions that they took. I don't think that would ever have had happened on our Commission. We were very different politically. We had to battle it out with each other. And, so there was a diversity built in and no effort to surround or overcome that diversity by imposing a particular political view.

I worry that these bioethic commissions are increasingly considered useless or are marginalized by people in the field of bioethics because they have become viewed as instruments for political purposes. And, I don't think that the National Commission was viewed that way. Certainly the National Bioethic Advisory Commission did a lot of important work.

Promulgated some important reports, and they have entered into the discourse of people who do bioethics. But, how much impact they have had on the actual practice of bioethics is not clear to me. Whereas it is very clear to me that the National Commission's legacy of impact on practice in the field of Human Subjects Research has been enormous and extensive over time. If I may add one concluding comment.

INTERVIEWER: Yes.

MS. LEBACQZ: I really would want to stress that I consider it a privilege that I was invited to serve on that Commission. It was long and hard work, and quite frankly, took a toll in some ways on the remainder of my work. It was difficult for me to publish my own things as a young scholar because the work of the Commission was so demanding.

And, it was very hard to have a personal life at all when you're on the road at least two weekends out of every month for this particular task. And, at least one other weekend usually went into reading all the materials that we needed to read.

So, it took away from some personal agendas and goals, but it was a tremendous experience. And, I had excellent colleagues and wonderful connections that I retain to this day from some of the people who either were on the Commission or served as consultants on the Commission. I was lucky.

INTERVIEWER: It is quite remarkable that the personal contacts have remained and that there is going to be a reunion of so many of the former Commissioner's. That there was a reunion in Milwaukee earlier this year.

MS. LEBACQZ: Yeah.

INTERVIEWER: So, that is a wonderful tribute to the cohesiveness of the group.

MS. LEBACQZ: Yes, and we have made no deliberate effort to stay in touch over the years. And, in fact, some of us had lost contact for some time. But, then we rediscovered each other in one context or another. Pat King and I, for example, had not seen each other probably in almost 20 years when we found ourselves working together on a group that had been set up by the Hastings Center.

And, as soon as we saw each other it was just like old days. Our hands would go up at the same time, and we would look at each other, which of us is going to answer this question. And it really was just like reliving the Commission all over again. It was wonderful. So, thank you Leroy.

iINTERVIEWER: Thank you Karen.

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