June 17 and 18, 1998. Interview with Alexander Morgan Capron, LLB, University Professor of Law and Medicine and Co-Director of the Pacific Center for Health Policy and Ethics, University of Southern California, Los Angeles, California. The interview is being conducted by Judith Swazey at Professor Capron’s office at USC.

SWAZEY: Alex, let me start out with sort of an icebreaker question by asking you how you would define or characterize bioethics? What does the word connote to you?

CAPRON: To me bioethics is an interdisciplinary field, in other words, not a discipline that is a part of philosophy, or part of medicine, or part of public policy, or part of social science, but rather the area where those different fields come together to examine the questions raised by developments in medicine and the life sciences and to ask questions of value and consequences about those developments.

SWAZEY: Can you see various phase movements that bioethics has gone through? Is it just the same now as when you got involved in the field or has it changed?

CAPRON: It has changed in a number of respects. I think the two that stand out the most are, first, that it has moved from something which was of interest to a relatively small group of people. I think the issues were just as important then but the range of interest was much smaller. People in medicine and the sciences and nursing who took an interest in the field were regarded as having moved away from the serious aspects of what they could do into something which was not so serious, and it’s become something that is now constant front page news. When the stories used to run in the early days, it was unusual to have someone identified as a bioethicist commenting. You might have a physician, you might have a lawyer, you might
have philosopher, who was called upon by a reporter to comment but they weren’t
identified as a bioethicist, it wasn’t something that had public currency. The other
development that has begun to change the field, and I think is very different from
the late 1960's, early 1970's is the professionalization, and the fact that the
definition I offered you a moment ago I think wouldn’t be accepted by a group of
people, particularly those from the philosophical side, who are now seeing
themselves as having a profession of bioethicist and with that something of an
academic discipline. You can get a degree in bioethics now both at the doctoral
level and at the applied masters level to become a hospital bioethicist or
consultant, and as an undergraduate. Through the years and especially more
recently I’ve seen resumes from people looking for work who have their bachelors
degrees in bioethics, or in science in society with a concentration in bioethics, or
in philosophy with a concentration in bioethics. So it’s begun to emerge in that
way. Of course, the Society of Bioethics Consultation and then the joint task
force of what is now the...I can’t remember the name of it at the moment, but the
successor for the Society for Health and Human Values and the American
Bioethics Association...

SWAZEY: The American Society for Bioethics and Humanities, I think that’s the new
incarnation.

CAPRON: ... with it’s notions of, or its feeling out the notion of, having explicit credentials
and qualifications, which is understandable to the extent that it is itself a reflection
of the first phenomenon. One of the reasons that bioethics is more in the public
eye and taken more seriously is that people in institutions, particularly hospital
administrators and others, are actually hiring and listening to people who call
themselves bioethicists. And you don’t want just anybody who happens to claim
to be a bioethicist to be playing that role if their comments and even
recommendations or orders, as it were, in the chart of a patient are going to have
an effect on what the nurses, and physicians, and family, and patients decide to do.
It’s understandable to say, “Well, wait a second. Who knows enough to play that
role, who’s been trained enough? Who’s immersed themselves in the issues well
enough to do that?” And so then you get this push towards, “Well, we ought to
certify, and what are the academic preparations that you would want to have and
the clinical exposure that you want to have?”

SWAZEY: Do you consider bioethics to have reached a point where it is a profession?

CAPRON: No, I don’t consider it that. And in a certain way this development that I just
described, which is towards it being called a profession, I think in the long run
will diminish it. Both because what has always been to me the exciting part of it
is talking to people from other fields, and realizing like the fable of the elephant
and the blind man, that we see this reality very much through our disciplinary and
professional eyes and that we learn so much when we recognize other ways of
seeing that same reality, other ways of describing what is and is not an issue in a
certain situation. There's no way, it seems to me, for a person who has become a
professional bioethicist with that as his or her background, not to simply end up
with one of those perspectives. It's not as though if the field encompassed all the
perspectives at the beginning, that by calling yourself a bioethicist you
automatically encompass that, that perspective comes about through the training.
One of the things that I always enjoyed so much when I was teaching at Penn was
a law school seminar initially, but where I had permission from the medical
school and from the graduate school to offer it as a seminar for medical students
and graduate students, and occasionally Renée Fox recommended a highly
talented undergraduate student as well. Usually the students came from the social
sciences and only very occasionally from philosophy actually. One of the things
that I found so interesting then was these were typically people who were only a
couple of years into their profession and yet they, sitting there in that classroom, at
first could hardly converse. It wasn't just doctors distrust lawyers and lawyers
are skeptical of doctors, it wasn't a personal antagonism. They would simply read
the cases that we were reading for the week or talk about a problem, and already
have their disciplinary or their professional blinders on. The way I had organized
that course was to have the first 7 or 8 weeks doing readings and discussion, then
to have them presenting projects that they worked on. The projects were typically
two law students, a medical student, and a graduate student working together.

They would take a particular issue like surrogate motherhood, which wasn’t even
called surrogate motherhood then; it was a hypothetical which I spun out of an
Ann Landers column where one twin sister had written in that her sister was going
to carry her baby for her. Actually not her baby; this was pre-in vitro fertilization
so it was that she was going to get artificially inseminated by the infertile twin’s
husband and carry the baby, and so we used that. What should the state do about
that? Should that be okay? Should there be any regulation of it? And so we had
the team working together and by then they had learned to converse. But it was
startling to me that people that early in their professional lives, not having seen
patients and clients extensively-- it wasn’t as though they were years and years
into their careers -- had come to see things already so differently.

SWAZEY: Socialized by their training.

CAPRON: Yes, socialized....

SWAZEY: Do I hear you saying that as the professionalization of bioethics is being attempted
it primarily is a philosophically-based effort?

CAPRON: Well, I suppose it has still two currents. The one on the academic side I think is
driven by philosophy. I say that sitting here at a university where I can’t interest
any of the philosophers in becoming bioethicists. We have some people from the
department of religion who work with the programs but only recently have I been
able to persuade a couple of people, and not even to do the very applied, but to do
some of the more theoretical issues about genetics and disease and so forth. But
overall I think around the country that Stephen Toulmin’s famous article about
how medicine saved the life of philosophy, still has a lot of currency in sort of the
bread and butter philosophy departments and programs because the number of
people who are going to go on and be analytic philosophers, or logicians, or
whatever else is relatively small. So if you’re running a philosophy program, in
many places, the notion is very attractive that you could have graduate students, at
least at the masters level and maybe beyond, come through and then go on and get
jobs because people want to hire people in applied ethics, of which bioethics is the
most well known and glamorous. It’s a growth industry; corporations are also
hiring people in ethics to worry about what’s called corporate compliance issues.
So I think that there is this drive on the philosophy side. The other current of
course, is the people who come from medicine and nursing and the other allied
health professions, and out of personal interest decide that they want to
concentrate on some of the ethical issues. They see those issues as compelling
and many of them will go on and get some additional academic qualification, a
masters degree. Many of them also don’t, but get immersed enough in it so that
they become their institution’s ethicists. They serve on committees, or they serve
as ethics consultant for the institution. In effect, they are playing the role of a
professional, not in the sense that it’s a closed off group, and not that they’ve
gotten to the point of setting educational requirements and examinations and so
forth, and doing self-discipline and all those kinds of things that are the true mark
of a profession, but they are moving in that direction and they are coming out of
the medical side. I actually suppose that in the long run there may be a struggle
between those two currents and the people on the philosophical side who can
make a strong claim of bringing the analysis and the structure to the table may
very well prevail in saying, “If you’re going to come from the medical side that’s
wonderful because you bring a lot of clinical knowledge, but if you don’t come to
us and get the stamp of approval that you have actually mastered this, then you’re
just a doctor with his or her own personal opinions about what’s right and wrong
and that’s very well and good but don’t call yourself a bioethicist. We have the
franchise.” That struggle may happen, but I think for the moment, however,
professionalization is coming out of both currents. There’s a minor current of
contribution, I suppose, from people who are trained in law as well. But I think
those from the law have overall tended not to be the in-the-hospital, clinical
bioethicist. Les Rothenberg at UCLA is an exception to that; Nancy Dubler in
New York and a few others. But most of the people in law who are identified as
bioethicists, George Annas, Hal Edgar, who was sort of out of the field for a
while, Lori Andrews -- you know the usual suspects -- are academic lawyers and
write about the field but don’t, on a day to day basis, walk the corridors and carry
the beeper and so forth. They may serve on an ethics committee for example but
not clinical bioethics stuff.

SWAZEY: Do you consider yourself to be a bioethicist?

CAPRON: Well, that’s a hard question. Obviously, I’ve been called a bioethicist for so long.

SWAZEY: Never mind what you’ve been called, these are two separate questions.

CAPRON: I understand that but I’ve been called it enough...just the way I’m called Alex. I
consider myself Alex, but for a very long time if people would say to me, “You’re
a bioethicist.” I would say, “No, I’m a lawyer who teaches law students and
medical students and is concerned with the social and ethical issues in science and
medicine.” I was partially, I think, resisting the notion that there was such a thing
as a bioethicist. My earlier comment, I saw myself coming to the table of
bioethics as a person from a particular background but that didn’t make me a
bioethicist. And I didn’t know what a bioethicist was.

SWAZEY: I think that’s the same reaction Renée and I have had for years and we still have.

People keep saying I am the senior bioethicist in the state of Maine, and I tend to
look around wildly to see who they’re talking about. It’s partly what Russell
Baker wrote about that wonderful column a few years ago, “The Ethicization of
Everything.” So if you’re interested in values and the issues raised by the
advances in biology and medicine, you’re labeled a bioethicist.
CAPRON: Right. And so your reaction is somewhat the same, you get labeled that enough so you stop protesting. It’s not offensive, being called a bioethicist, I just sort of thought it was either meaningless or silly for a long time. And I guess to take a slightly more serious cut on it, and not to yield the field to the philosophers, I thought that if one had done formal training in moral philosophy and was an expert on ethics which mostly at that time meant metaethics and not the applied decisions, you could be called a bioethicist. Even today bioethics, I think, makes very little contribution to ethics at the level of truly personal decisions. This is actually, I think, the influence of the law, and my piece in *The Encyclopedia of Bioethics* says that the law has had a very big influence on bioethics but it’s mostly been on the analytic side and to push toward proceduralism. To sort of say, “Well, we have little to say about the judgements, about what’s the right judgement, what your choice ought to be here. But here’s what you may choose.” The dictum that is often repeated is that bioethics talks about your right to do things, not what’s the right thing to do. And to a certain extent where something becomes very familiar and very routinized, we begin to say what’s the right thing to do. Certainly, it’s the right thing, with a patient in a persistent vegetative state to not press further treatment after a certain point. You’re not doing anything for that person. I think that would be regarded as the consensus in medicine and nursing today and among most families and among most people. What that has
meant is that the presumption that the law brings to the table, as it were, has changed. For a long time judges basically, in many states, were saying, "How can you disconnect the feeding tube? That would kill the person and that would be wrong, but we would allow it if the person had made it really clear." And then the presumption shifted around and you almost would have to say, "I want a feeding tube for the indefinite future...for thirty years", in order to get one. The presumptions really shifted around. So there are in some ways those individual decisions are pushed but I think even in that case, if you had said, "This is what I want," we wouldn’t say, "Well, that’s not the right thing to want.” The way we would not say, “If you want to have sex with children, that’s alright to have.” No, that’s not alright. You can’t do that. Or you want to murder someone, you can’t do that. That’s the wrong thing to do. We have no questions here, that’s wrong to do! So there are limits that society imposes, but I think for the most part bioethics has talked about “this is the circle of the permissible, and these are the factors that the doctors and nurses should take in to consideration.” And if a family says, “Well, we can’t disconnect because that would be wrong but we wouldn’t have started,” then bioethics can contribute, “Oh no, let us assure you that the decision not to start and to stop are really the same decision. They just feel a little bit different but you’re not doing a wrong and indeed it probably would be better to try, but don’t feel locked in.” You’d consider that melioristic in making things
clear but it doesn’t say to people you’re wrong if you end up taking all that into
clear but it doesn’t say to people you’re wrong if you end up taking all that into
account and still say, “Well, we don’t want to discontinue.” Joseph Quinlan had a
different reaction to his daughter being on a feeding tube than Joe Cruzan. And
one father, Mr. Quinlan, after they had withdrawn the respirator, when asked,
“Why don’t you withdraw the feeding tube?,” he said. “But that’s her
nourishment!” And he wouldn’t do it. Whereas eventually the Cruzans said, “I
know Nancy wouldn’t want this and we’re going to pull that.” Both of them had
daughters in the same kind of condition, young ladies who were PVS. We don’t
say either one was wrong. They were both within that circle of the acceptable and
they just had a different take.

SWAZEY: So I take it after all these years you have accepted the appellation bioethicist.
CAPRON: I’ll try to make my answers more direct. (Laughter)
SWAZEY: No, that was an important discussion. So who can be a bioethicist? You’ve
talked about the push for certification.
CAPRON: In my view, anyone who contributes to thinking in the field could be called a
bioethicist. I’m not one who wants right now to set qualifications. I also think
that many of the kinds of qualifications that we are going to find on the academic
side are not the ones which would assure you that the person is qualified to do
what he or she is being hired to do. Where you get to discourse, that’s a self-
correcting thing. If a person is writing a paper and it doesn’t say anything, you
ignore the paper and it doesn’t get published or something. If a person is hired by
a hospital because they have gone through XYZ program and they have a masters
degree in bioethics and they are a consulting bioethicist, and they don’t have
judgement, and they don’t understand the field, and they don’t understand what
the issues are because they haven’t seen enough of it, or they just don’t get it
because some people just are tone deaf or something, having the degree isn’t
going to make any difference. Someone else without that degree who is sensitive
to the issues and has experience and has good judgement would be a better person
to turn to for advice. That’s true in every field, we all know that.

SWAZEY: It also seems to me, in talking to people who do clinical bioethics as their job, that
probably 90% or more of what they do is really a lot of counseling with patient’s
and families, dealing with tension between doctors and nurses, etc.

CAPRON: Right, a lot of it is a chaplaincy role.

SWAZEY: Yes it is, which means that you don’t have to be a “bioethicist” to do that. So I
have a little trouble figuring out what certification would involve. I just can’t
envision what sort of certifying exam you would take to become a clinical
bioethicist or a bioethicist generally.

CAPRON: Right. We at USC call our Ethics Committee an Ethics Resource Committee, in
part because we wanted to get away from the implication that it was like a court
making decisions...and that’s a group of 15-20 people. Each month there are three
people who are designated to be that month’s team, an ad hoc group that’s called
the Case Counseling and Consultation Group, and the emphasis is on counseling
and consultation, recognizing that most of the problems come up that way. Ron
Cranford used to say, years ago, that he was successful at Hennepin County
Medical Center in providing the bioethics consultations that he did because his
secretary seemed to be the only person who could get all the medical consultants
in one room at one time. And 90% of the time when they got there it turned out
the reason the family was saying one thing and the attending was saying
something else, was the family had heard from this and this and this consultant
something that either they hadn’t understood or the consultant, more likely, didn’t
understand the whole case. They were saying, “Oh sure, we can fix her lungs, of
course, the lungs will be fine.” And the family was hearing, “She’ll be fine.” And
the endocrine person was saying, “No, it’s not going to work, in the end it’s all
falling apart.” They were thinking the endocrinologist is the crepe hanger and is
being negative, whereas they were hearing from these other doctors “it’s fine”
because those physicians were just looking at the organ system that are their
specialties. You get them all together, get that consultation and then suddenly
there’s a picture that makes sense to everybody. But that wasn’t even counseling,
that was just consulting and communication. So, I agree with you, it’s hard to
know how you would figure out those qualities. I have had a few people
privately, not for fee, just call me up and describe a desperate situation and say, “Can I come and see you?” And with some of them I’ve sat in my office for a couple of hours and hardly said a word, they just need someone to talk to. In the end it’s all clear to them, and I’ve hardly said anything. I get a call a few weeks later, everything worked out and this is what happened and thank you so much...it was just wonderful.

SWAZEY: You’re right, they don’t really have a chance to think it through out loud.

CAPRON: Right, and just with someone who is going to have a few bearing points along the way. And that’s not doing philosophy, I wasn’t doing law, I wasn’t doing medicine. I don’t know what I was doing!

SWAZEY: As you said, it’s closer to the chaplaincy or a good social worker in many ways.

CAPRON: I think when you sometimes hear that somehow ethics hasn’t kept up, which is a very common refrain every time there is a new medical development, it’s often that ethics and the law haven’t kept up. They’re like the slow children in the family and medicine and science are running ahead, while the others aren’t keeping up. When you get down to actually thinking about the issues, it turns out that if we can figure out where the issue connects with our ethical values, the values and the judgment and the guidance are probably already there because we’re much more likely to consult timeless principles and timeless writers and thinkers. I mean, you don’t go to Hippocrates for medicine but you might go to
Moses, or Jesus, or Buddha, or Socrates, or Kant for ethics.

SWAZEY: There isn't too much new under the sun in that area.

CAPRON: Right. And I think a lot of what people are confused about, even in the chaplaincy role, is what their own tradition's values are and what general societal values are on a subject. Once they can see how that fits they don't have a lot of problem making the decisions; then it becomes more comfortable. It's just this notion that it's so new as a subject or as a particular dilemma that "I've never thought of before, I don't know where to go." Well, you do know where to go, it's really right there. You have a sense of your relationships; parents to children. What it means to have a full and good life and so forth. You have that already and what it means to protect life and vulnerability and respect. Those things are there and it's just a matter of tapping into them.

SWAZEY: I want to come back to some of these questions towards the end. Let me switch to the view and how you got where you are today. Most people have told us that their entering the bioethics was serendipitous. Tell me a little bit about your family background, just to give some context. Where you grew up and what your parents did.

CAPRON: I grew up sort of all over the place. My father is an academic economist and I was born while he was in the war. I was born in Hartford because my mother's family came from there. I was almost born in Texas, where he had been stationed before
he shipped out to Europe, but my mother went home to Connecticut. In my early years, my father was briefly in Washington and then went to graduate school at Harvard. So I went through pre-school in Cambridge. My sister was born there and we went to Berry Brazelton as our pediatrician.

CAPRON: We then moved to Champagne Urbana, where my father taught at the University of Illinois for a couple of years. I started elementary school there and my next brother was born there. Apparently there was one of those academic freedom things that came up for either the chairman of the department or the dean, I can never remember. Red Smith and a bunch of the faculty resigned in anger and we moved out here to California. My father went to work for Rand and we lived in Westwood near UCLA and my youngest brother was born here. And then my father went off for a year, to Palo Alto as a visiting professor and came back here for a year and then they invited him to come up to Stanford. So then I went through junior high school and high school in Palo Alto. Then in 1962, when I graduated from high school, my father had an offer to go back and work for Jack Kennedy’s administration. They had postponed acting on it until I graduated from high school, which was also when my sister was graduating from junior high school and my next brother was graduating from elementary school. We were in these nice cycles...very well timed. So we moved and I went to Swarthmore and my family moved to Chevy Chase. My father worked first at the Council of
Economic Advisors and then was the Assistant Director of the Budget of the
Bureau when Kermit Gordon was the director, back in the days before it became
the Office of Management and Budget in the Nixon administration. After a
couple of years there he went to Brookings, and then went off to the Kennedy
School at Harvard, and then became chairman of economics at BU. They’ve now
retired. My mother through all of this, besides what I now recognize as being the
parent of four young children -- having three young children myself; I have a 22-
year-old and my three little guys at home -- my mother somehow was setting up
households, and making friends, and getting us all off to school, and being an
incredible volunteer. My parents had met at Swarthmore and my mother had
worked shortly after the war for The New York Times, but thereafter she had
about thirty years of not working outside the home, except running every
peace-related, fair housing, Democratic Party, Unitarian Church, etc, thing. How
she did it all, I’ll never know.

SWAZEY: Is that why Swarthmore?

CAPRON: Yes. I guess like a lot of eldest children, I have and had strong identification with
my parents and they had a very good education there. By the time I was thinking
of college, the other major choices that I had were not yet co-educational, and I
wanted co-education. And I liked the idea of a small college, and Swarthmore
was at the top of the rankings in terms of colleges.
SWAZEY: What did you major in?

CAPRON: The honors program at Swarthmore, which was about 40% of the class, I guess, was then still in the pattern that it had been on since the 1930's, of eight seminars in one's junior and senior year, two weekly seminars for those last four semesters, where all the examination was done by faculty from other universities, so-called outside examiners. The usual pattern was to have four seminars in a major and two in each of two minors. Following in my father's footsteps, I was an economics major. But I wasn't a political science minor. (There wasn't sociology, by the way, for Renée if she's listening to this tape.) There was history but there was no sociology or anthropology department at the time. There were a couple of people, I think from Penn, who came out and gave individual, occasional classes or something. Then shortly thereafter there was a great agitation among the students to get anthropology and sociology into the curriculum, and it was around that time that the departments were created. But in any case, I fastened on the idea of being a history and English minor. The chairman of the English department was away when I was a sophomore, and whoever was guarding the gate let me in. They usually did not allow people who were economics majors to be English minors because one was in the division of the social sciences and one was in the division of the humanities. Even at a small college like Swarthmore, the idea behind it was that the eight seminars that you
were taking were supposed to somehow “integrate.” By the time you were done, you would have learned more than these eight particular topics.

SWAZEY: Talk about disciplinary boxes!
CAPRON: I know, absolutely! Part way through, in my junior year, I decided I was really liking the history at least as much as the economics, and so I developed a special program where I took, three history seminars, three economics and still did two English. The two English were Shakespeare, because I thought that the professor who taught Shakespeare was wonderful and I just loved Shakespeare, and American literature. And I took American domestic history and American foreign history. I was sort of trying to get some integration because most of the economics I was doing was macroeconomics stuff like economic policy issues, national economics. So there was some integration; it was still pretty farfetched but I got through it all. Then I went directly, the next year, to Yale Law School.

SWAZEY: Why did you decide on law?
CAPRON: I spent a lot of my time in college in jail because of civil rights demonstrations starting my freshman year. There was a lot going on then in Cambridge, on the eastern shore of Maryland, which was really still very much the Deep South. That summer, in 1963, I spent some time going over from Washington. I went back out to California and then I came back East. What was called the Swarthmore Political Action Committee, SPAC, became an affiliate of Students
for a Democratic Society, SDS, which had just been formed in Michigan a year or
so before by Tom Hayden and others. At Swarthmore it was an interesting
conglomeration of people, though I don’t think I realized it fully at the time.
There were at least three sorts of traditions. There was the pacifist tradition, the
Quaker tradition, and people coming out of that background. There were the red-
diaper babies, the children of communists and quasi-communists, who had grown
up particularly in New York, the little red school house and the whole thing. And
then there were those of us from the liberal democratic background who were not
Quakers and not children of the old left. The whole thing about SDS and so forth
was that it was “The New Left.” The reason for emphasizing that term was sort of
the non-Stalinist left. These came all together, and the major fodder for it, I think,
was the group that I came from. But two or three of the principal leaders were the
children of the old leftists and people like Patch Dellinger, who’s a classmate,
whose father is Dave Dellinger, who’s obviously from a pacifist tradition. I had
been a conscientious objector; one of the things that attracted me about
Swarthmore was the Quaker tradition. Anyway, we had the exposure to what was
going on in Cambridge and a lot of arrests there and going back and forth from
there, and then we turned our organizing efforts to Chester, which is the principal
city of Delaware county, which was then beginning its downward spiral. It was
where SUN Ship Building and SUN Oil were headquartered. Delaware County is
very important politically because, although it had this big urban and minority population in Chester, it also had these very rich suburbs and it was the home of John McClure, who was a power in the Republican Party. I always heard it said that Eisenhower was really tapped to be president in McClure's living room there. McClure had a machine so that he could deliver the votes of the county. It was literally old-fashioned vote buying. On election day people went up and down through the ghetto passing out one dollar bills.

So we went through some of the housing projects asking people what problems they had and one of the main problems were the schools. So we started off organizing around the schools and this was the kind of a situation where the schools were basically de facto segregated, with black kids in schools so old and crowded they held classes in boiler rooms. There wasn’t enough space and so they had a kindergarten, literally, in a boiler room... with a boiler. This was an old-fashioned brick schoolhouse. So out of those marches, where we closed the schools down and troops of families marched to downtown Chester to protest these things, the police came in sweeps, and we’d all be hauled off to jail. At various times I spent a week or a couple of weeks at a time in an actual prison; the jails weren’t big enough so they took us off to a state prison. Tony Amsterdam, who was then on the faculty at the University of Pennsylvania Law School, was working with the various civil rights groups. Most of their effort was
obviously concentrated on the Deep South, but Chester and the eastern shore of Maryland were examples, to them, of similar problems. And he seized upon one of our cases as a case to argue for the right to remove cases from the state courts to the federal courts because of the inability to get a fair trial. Just having the exposure to that work that he was able to do, and he got us all out of jail in the process, was part of my inspiration. I went down to Selma and was part of the Selma March and things like that. I was doing these kinds of things but it was just a realization that lawyers played a very important role. My grandfather, for whom I'm named, my father's father, who's Charles Alexander Capron, and was called Lex Capron, was a lawyer in New York. He had died when I was in fifth grade, I was about 10 years old, and was always someone I liked a lot. So I sort of had the family background a little bit, I suppose. I also realized I was not a great mathematician, and that the future of economics was probably in heavy duty quantification. So I knew that I would probably do better not going on in economics, and yet what had drawn me to economics was the policy issues. Then in choosing law schools I thought Yale was attractive because people I knew said it was the best law school and because it was small like Swarthmore. It also had a very strong emphasis on the social policy issues and law, in effect as part of the social sciences, which I think is overstated, but that was the Yale tradition at the time...social activism and so forth. Whereas Harvard Law School at the time was
still very much a Wall Street oriented school -- get the best and the brightest from
around the country and send them back to be, if not the lawyers of Wall Street,
then the leading lawyers in Des Moines, the leading lawyers in Portland, and so
forth.

SWAZEY: What did you see yourself doing when you came out of law school?

CAPRON: I thought I would work in a civil rights organization. Indeed, my first summer I
worked for Marion Edelman, Marion Wright as she then was, in Mississippi. I
was there on an internship program of the Law Students’ Civil Rights Research
Council. There were a number of us who went South with that. When I got to
Jackson she said to me that she thought, because of my experience, she would
send me out to Marks, in Quitman County, Mississippi, which is the poorest
county in the United States, where I lived with a family. I thought my experience
that she found relevant was my civil rights experience, but it was really the aspect
of the civil rights experience of realizing that people in this situation fight a lot
and can’t come to agreement. And she thought I would be patient in working
through with them because there were a couple of suits that she wanted to bring.
One was a municipal equalization suit, because the city had basically re-drawn its
boundaries to exclude the black population. It was just remarkable. The other
remarkable thing to me was how, if you were at all a straight forward, polite,
white person, you could get amazing things done there, even though you were a
northerner. This is the disadvantage of having gone to Yale Law School; in my property class we didn’t learn a lot about conveyancing and deeds, we mostly talked about property as an abstract concept. So one of the things I had to do was figure out who owned what property in order to make out the evidence that was going to be necessary to show that the city had managed to extend its boundaries in a certain way so as to provide municipal services mostly just to the white people. The black people a few feet away, who were on the other side of a culvert or something, got no electricity or running water and no sewers, or whatever. I actually found that the county clerk for Quitman County was very helpful. The staff showed me how to read all the property rolls. (Laughter) So that was useful and helpful! But otherwise, after about three weeks up there I went back to Jackson one time and I said, “Marion, I’ve got to get a different car!” She had rented me a red Fiat. I don’t think there was another foreign car north of Tupelo, Mississippi. There certainly weren’t any red Fiats...it was like screaming, “OUTSIDER!”, like an arrow was pointing there. When I’m driving down the road in the evening and I notice a pickup truck with a shotgun across the back window following me, I would like to be able to blend in better. So I think I ended up with a small Ford instead.

SWAZEY: Did you hook up with David Bazelon before you clerked for him?

CAPRON: No, I did not.
SWAZEY: How did that come about?

CAPRON: In those “old” days, in 1968 as I went into my third year, various of my professors said, “Well, what do you want to do? Where do you want to clerk?” I said I hadn’t really given it any thought. I had taken a psychoanalysis and law class with Jay Katz and had some general interest in that field. I found the class extremely interesting. Joe Goldstein and Abe Goldstein, had been clerks, Abe being Bazelon’s first clerk and Joe a few years later. Joe, of course, was very deeply into law and psychoanalysis, and he and Jay and Alan Dershowitz had a book on psychoanalysis, psychiatry and law. Joe said to me, “Why not think about Bazelon?” So I gave him my resume and they had two or three people who I guess they screened and then I went down and met Bazelon. At the same time there was this arrangement that sort of was a two-step clerkship, to clerk for Abe Fortas. And so I met Fortas, but it was clear to me, this was by then my senior year (1968-69 school year), that the decision was really being made by the people in New Haven. I think they were sort of the delegated agents for Fortas and Bazelon. I think Bazelon and Fortas said, “Find us the right law clerk. We’ll meet him, find out he doesn’t have two heads so that we can talk with each other, but basically the criteria is that he has your stamp of approval.” And so I got that clerkship. My senior year I met and went out with Barbara Brown, she was a first-year student who had come from Radcliffe, and that summer we decided to get
married. We spent the fall commuting back and forth. But Fortas had just left the
court. Johnson had put him up for chief justice and then the Republicans had
stalled seeing if they could recapture the White House. During that process it
came out that he had taken money from Lewis Wolfson’s Foundation, and
Wolfson had these connections in Las Vegas which was still then regarded as
mob- dominated. It was just a mistake. So Fortas, under that criticism, resigned.
So again, the folks at Yale, principally Jay, said, “Why don’t you come back,
teach at Yale, and then Barbara won’t have to transfer for her final year.” The
thought was, she’d spent the spring of her second year, when I was with Bazelon,
working for the Center for Law and Social Policy in Washington, which had just
been established that year. She was in the first group of students who had what
we would now call “externships.” It was funny; when Yale agreed to allow about
four or five students to do this, they were going to call it “the semester off.” Then
they said, “Whoa, that doesn’t sound good!” So they called it the “intensive
semester.”

SWAZEY: This was after you had clerked for David Bazelon?

CAPRON: No, this was my year of clerking for David, 1969-70, that she was in D.C. one
semester. And then, instead of staying there, with no position left with Fortas,
their suggestion was that I would go to New Haven in July 1970 and she could
return to finish at Yale. So it made a lot of sense. I went back to Yale and I
taught a couple of courses each year for the next two years. I also taught a law
and psychiatry course at the University of Connecticut, in West Hartford. After
Barbara graduated in June 1971 she clerked for Joe Smith, who was on the
Second Circuit, and whose chambers were in Hartford. So we had those two
years 1970 to 1972. It was during that time that I was working with Jay on the
human experimentation book, and beginning to meet with people about genetics at
the medical school, and to write on that. In 1970 I met Dan Callahan and got
invited to become a founding fellow of the Hastings Center. Soon I was in three
other research groups and spending a lot of my time on Hastings activities. I was
on the Board and very quickly became deeply immersed in that, particularly, of
course, my friendship with Will and Betty Gaylin.

SWAZEY: Let me go back to your clerking with David Bazelon. Was that something that
influenced any of your subsequent work?

CAPRON: Well, it influenced my subsequent work in that it involved the whole notion of
how law interacts with an expert discipline. The year that I was clerking for him
he was the President of the American Orthopsychiatric Association, the largest
professional association dealing with mental health in the country. I didn’t spend
a lot of time on that activity because he had hired Barbara Cohen, who had just
graduated from Georgetown Law, to work with him on that. She wasn’t a regular
clerk to start off with, but she was wonderful and soon was doing everything else
that the other law clerk and I were doing. Although David was deeply involved in it, it was clear by then to him that the dream that had laid behind the Durham decision, dispensing with the McNaughton test for insanity and substituting something which was intended to allow psychiatrists to talk in their own terms, and educate the jury, and bring in a mental illness view, rather than the right-wrong view that the McNaughton test had had, wasn’t working. He also went to the Soviet Union on a tour and came back not only full of the abuses of Soviet psychiatry, but very much bringing home to American psychiatrists the abuses of their own field. A lot of the things he had been doing in the years before that had involved cases coming up from St. Elizabeth’s Hospital, which was the District’s mental hospital. In those cases he pioneered in applying procedural civil protections to the rights of mental patients to make choices about their treatments, not to be unduly incarcerated, to have fair hearings, and so forth -- all the basic things that were happening in the 1960's vis a vis welfare and a lot of other programs where people are at the mercy of government bureaucrats, and the kinds of administrative law rules that were being developed had been developed for industry dealing with the Federal Trade Commission, Federal Communications Commission, and the like, were being brought over to psychiatry. And Judge Bazelon in effect said they are equally applicable here. So I guess I picked up from him some of the skepticism about the ability to rely on experts to do the right
thing, and the risks of professional dominance and the abuse of power. As it has
turned out I haven’t spent a lot of time in the law and psychiatry area itself. When
I got to Penn a little later I did for one or two years teach a course with a
psychiatrist on the faculty there, as I had at Connecticut, but I didn’t end up
writing about law and psychiatry because the other issues just became much more
interesting to me. So I guess it was my introduction to law and medicine, and that
was partly because of Bazelon and partly what I brought to him. He encouraged
me, really tried to get me to accept the head of the Law and Medicine Center at
BU, with which he was then very involved, as you know. When I was back in
Connecticut at Yale and then considering what to do as Barbara’s clerkship came
to an end, where we wanted to go, what we wanted to do, he tried to get me to
take the directorship at BU. I considered it but in the end didn’t do that.

SWAZEY: Talk to me some about Jay Katz. I assume you met him when he was one of your
instructors in law school, and I assume he was a major influence in your life’s
work.

CAPRON: Yes, I met him in the law and psychiatry course. I think in the work that I’ve
done, Jay is one of the two or three major influences.

SWAZEY: Who would the others be?

CAPRON: Initially David Bazelon, and I think on some levels probably Will Gaylin just in
terms of encouragement, and Morris Abram, who was the chair of the President’s
Commission. Each in a very different way. Probably on the substance of what I’ve done, Jay is my major intellectual mentor. Should I free associate about Jay Katz?

SWAZEY: I would really like you to free associate, and talk some about what it was like doing Experimentation on Human Beings, which certainly is still one of the magisterial books in the field. Renée and I also wondered if you were involved in any of Jay’s interactions with Henry Beecher?

CAPRON: Well, I wasn’t involved as an intermediary. He had begun the book several years before, and when I came to him he had Eleanor Swift (who graduated in 1970) as his student research assistant. He made clear to me that he envisioned me playing a larger role, on the book, which I did. We sat down and reconfigured the book entirely at the beginning of my work with him. That was, of course, a huge education for me because I hadn’t taken the human experimentation course when I was there. So it was a matter of learning the materials and then of spending the kinds of hours one does early in one’s career just immersed in the library and so forth.

SWAZEY: Was it mainly a conceptual or analytical reconfiguring?

CAPRON: It was the analytic flow of how the materials were going to be organized that we did. Obviously, since I was coming to it new, I was more of a sounding board at first for him. Having not studied the subject previously, I didn’t bring that legal
knowledge, so it’s not a reformulation that I initiated, but what it meant was that everything was up for grabs. There were huge chunks of things that had already been established and needed editing and pulling together, like the Nuremburg doctors’ trial. So it wasn’t as though we had a blank slate but it was a matter of reorganizing and rethinking how the questions would be asked. The basic four part configuration of the book emerged at that time. When we were done with the book Jay said to me that he wanted me to be listed as a co-author, and then came back and said that he had talked to a couple of his colleagues and was dissuaded from that, which didn’t bother me. I would’ve been flattered to have been a co-author rather than a “with,” but this was a project that he had been working on for a number of years. I think his enthusiasm for what I brought to it made him feel so grateful for what I contributed to it...

SWAZEY: What an educational experience for you.

CAPRON: You mean working on that? Absolutely! The other thing that we worked on at the time became the *Catastrophic Diseases* book. That’s where I first met Renée, because she was a consultant to that project, as were some physicians, and Guido Calabresi and Dick Zeckhauser, an economist from Harvard. Each person wrote a paper for us which we used in writing the book. The whole experience of writing about a subject, in this case kidney disease and heart disease and dialysis and transplantation and getting deeply into the technical side was fascinating. I went
out to the kidney dialysis units in Boston and New Haven and met Hampers and Merrill. This was all pre-entitlement, of course, back in 1970-71 early 1972, and so the issues of scarcity and the early technology and so forth were all part of it. Then learning from these consultants as they were bringing in sociology, economics, history, and the medical side was a wonderful experience.

Earlier I was commenting on how bioethics is the melding together of all these things. We were asking the value questions of who decides what? Who decides how much of this stuff we’re going to have? How are we going to pay for it? Who’s going to have access to it? When is a person dead? At this time I also was working on some of those issues with the Hastings Center. Jay never had a lot of interest in the Hastings Center. I think Hastings would have been interested in Jay if he had wanted to be involved. He is much less a group person than I, and so along side working with him I was working with the group on genetics, and the group on behavior control, and also principally the group on death and dying and the whole development of the standard for determining death.

SWAZEY: I think that’s when we first met because I was on that behavior control group.

CAPRON: Anyway, Jay’s influence on my thinking is something I can’t break down. The kinds of questions that he instilled. Put it this way: Jay is very much committed to the notion of people being enabled to make decisions and doctors communicating to them, as is Bob Veatch. For Bob it was kind of a crusade in that era, and Bob
was coming fresh to this as the first staff member at Hastings, right out of the
graduate program at Harvard. The difference is that for Jay it’s a human not an
abstract philosophical activity. And hence, it is full of all the problems of
communication, of transference, of unconscious drives and impulses, and all the
barriers that are inherent and that make the perfection that you can write out as a
lawyer or as a philosopher all but unachievable, but nevertheless worth thinking
about, talking about, trying to do something about. But being equally as skeptical
about the rules that are developed and the laws that are pronounced by judges and
legislators as about the medical ability to do it and so forth. And that, I suppose,
was what changed my perspective on all these things. In other words, I think that
a lot of lawyers and philosophers rather naively believe that when we describe this
consent structure and put it in place with incentives or penalties, there it is. This
is what informed consent is, write it out and so forth. Instead, as Jay taught me,
you need to be aware of all the reasons it isn’t going to happen that way, and that
if that’s the only thing you see here, you’re not describing a reality. I suppose
what I brought to that for Jay was an understanding of those legal doctrines and
how they get manipulated and how it isn’t unimportant to be concerned with
whether this is a battery tort or a negligence tort, and how that plays out or
procedural issues and the like. The way in which law also doesn’t spring full
blown from something. It arises in the intricacies of cases, and the way those
cases get brought becomes very important. This whole revelation we had from the brief of the American College of Surgeons which was the origin of the phrase “informed consent” in the Salgo case, tossed off by the lawyers for the doctors, not the lawyers for the plaintiffs. That began something which had implications far beyond what they thought when they were developing it, but it didn’t come out of philosophy and it didn’t come out of abstraction; it comes out of argument over cases. I see much more readily what he gave me more than what he got from me.

SWAZEY: One generally does what with a mentor.

CAPRON: Exactly. That was very formative because I think at least for my early years, I could’ve gone off and done other things. My early years basically cast me as a person who was going to be deeply immersed in these issues. My first major articles were on them. My first book, the *Catastrophic Diseases* book with Jay, was in this field. And then basically his encouragement to do work in the field, that it was a valuable field to work in. It’s much easier for people in law faculties, good law faculties, to be concerned with issues that interest them than it is, I think, in the medical area. In the medical area, this is where the field is now. You get on the frontier and take the next step, and if you’re off way to the side you’d better have something to show for it that can be recognized in ordinary terms or you’re in trouble. I’m sure among my law faculty colleagues at Penn there were some who said, “How is this law exactly? Yes, you’re writing about the
determination of death but a lot of what you’re writing about is organizational and making choices. This doesn’t sound like law. Where’s the criminal law, or the tort law, or the decedents’ estates, or corporate law. They’re recognized sub-parts of our field.” But no one ever said to me basically, “What you’re talking about is a hobby, go off and do that over there. You have to write in conventional fields if you want to succeed.” Instead, they liked what I did, and having the courage to do it and continue with it is something that Jay’s encouragement helped a lot.

Equally important in that process I think was what was going on at Hastings and meeting people like Harry Beecher early on in that process. He was a member of the death and dying task force, as were Bob Morrison and Leon Kass and Eric Cassell, and others, who were all extraordinarily smart and learned people and who thought these were difficult and interesting things to worry about, and that we could make a difference by what we said about them and how we thought about them. That itself was a huge incentive and sort of a collective mentorship of my early time.

SWAZEY: Let me go back to Jay and Harry Beecher. In the essay that Jay did in *The Hastings Center Report* for the Beecher Award he discussed his meetings with Harry and their discussions about clinical research ethics and so forth. Were you there for any of that?

CAPRON: No, I think that was in the period between 1966 when Beecher published his paper
and the human experimentation conference that became the 1969 *Daedalus* book.

I think that’s when most of that took place.

SWAZEY: Let’s talk some more about your early involvement at Hastings and some of those influences, and also about how you would characterized Hastings as to major Centers. How did you get to Hastings, first of all?

CAPRON: I got to Hastings because I met Dan Callahan, who I think was pleased to find someone in the law who was approaching it in a way that he thought was compatible with what they had just started trying to do at Hastings. In other words, this very thing that I was just describing of not taking a narrow, disciplinary, let-me-just-tell-you-what-the-law-is-thank you, like getting legal advice. Instead, I was analyzing and speculating and spinning out the hypotheticals of different situations. He said, “You should come to Hastings.”

SWAZEY: How did you meet him? What was the contact?

CAPRON: I met him through a conference at Airlie House where I was giving a paper, and he was giving a paper, as were Leon, Paul Ramsey, Arnold Motulsky, French Anderson, and very memorably, Joe Fletcher. All of those people became friends, but the people who I was most quickly closest to were Leon and Dan because they were, more or less, my age group. Certainly one of my most memorable early experiences was Leon reading his paper on “The New Reproductive Technologies” and bringing to it this almost prophetic vision - it wasn’t quite a
Jeremiad, but he was basically saying all the things that were wrong with these kinds of developments. He was very careful and clear about it but also very eloquent and very strong. Then to have one of the commentators be Joe Fletcher, who basically looked like Santa Claus without the beard. He had that beautiful white hair and those pink, rosy cheeks, standing there in his poplin suit and bow tie, and lacerated Leon, he just shredded him. All the time with a smile, but basically saying this is all indefensible garbage that you’ve said. I can’t even begin to do it the way he did it. Leon wasn’t crushed by it, he had answers but it was difficult. He was taken aback, it was difficult to watch this public evisceration. In the long run one might agree with some of what Joe said, and some of what Leon said, but the process was...

...Not the normal polite academic discourse.

No! But what they were talking about, what we were all talking about, very, very much interested me, and being offered the opportunity to continue that by coming to the Hastings Center was wonderful for me. It seemed to me that a lot of the people who were involved in the early Hastings Center came from a background that led them to be interested in one particular aspect of what Hastings was doing. Hastings was basically doing four things with two little side things. Dan’s work in population was still ongoing. And that, along with behavior control, genetics, and death and dying were the four major groups. The side ones were human
experimentation, a little interest in that, and, of course, interest in medical
education because Bob and Will were going down to Columbia P&S to teach
there. I didn’t come with an interest in any one of those but rather found them all
interesting. So I found myself in the lucky position, and I was young, no children,
and New Haven’s not that far from Hastings, of being able to go to meetings on
three of the issues without too much difficulty and inconvenience. The population
issue didn’t grab me as much. But it was a fascinating period with the behavior
control group, with Perry London’s wonderful ability to pull it all together after
we’d had knock-down, drag-out fights about lobotomies and electrical
implantations, and, Will insisting that none of these began to do what the
implantation of an idea could do. Likewise the genetics area, where we were
doing stuff that no one else was doing. We ended up getting a couple of articles
in *The New England Journal* on genetic screening and counseling and put together
two or three volumes of papers. The death and dying project quickly led to my
paper on “The Determination of Death.” Leon gave me such wonderful
comments on the paper that I asked him if I could put his name on it as a co-
author. It was sort of the reverse situation with Jay Katz, only I persevered there
because it seemed to me that he had helped with such extensive editorial
comments and additions.

And Hastings also had larger meetings, which were still relatively small;
these were sort of open meetings which were held at the Tarrytown Hilton where there might be 50 or 100 people. They also had the smaller meetings or conferences that were held up at that Tarrytown estate. Although Dan and Will talked about the fact that it was hard to get money, they managed, between Robert Morrison's connections, I guess, with the Rockefellers, and a few early grants. We got some early money from the National Institute of General Medical Sciences for the genetics work, because Fred Bergsma from NIGMS was interested in it, and some money from the March of Dimes. So we were able to meet, I guess it didn't cost as much. None of us, as I recall, ever got paid anything. You got room and board and transportation.

SWAZEY: We got room and board and the honor of it.

CAPRON: Right, exactly. I remember sitting around in a couple of those meeting rooms when we had more than a research group there. We had the Hastings fellows. One thing that stood out was that, there were only a small number of social scientists like Renée and Don Warwick. It became pretty obvious to me early on that at the Institute of Society, Ethics and the Life Sciences, ethics are the people from religion and philosophy, and the life sciences are the physicians and biologists. What is society? You would think that it would involve the sociologists and the historians, the economists, and so forth, but there wasn't a lot of attention being paid to serious social science, even then. I remember one time
when Renée said as much and there was a sort of an icy chill in response to that. But it was still an interesting mix despite that.

SWAZEY: You said that Will, of that particular configuration, was particularly influential.

CAPRON: Yes, but there were a number of people on the staff, principally Dan of course, and Bob Veatch, and then later Ruth Macklin, and Art Caplan, and somewhat Marc Lappé, and others who were wonderful people to work with. It was great that they had those people on staff. Dan has written so much, and a great deal of it I think has been the crucial work in the field, that he has been influential. It happened that Will and Betty Gaylin became my closest personal friends out of the Hastings group, and when I would go to meetings I usually stayed at their house. One of their daughters was at Penn and the other one was at Swarthmore. So there were those kinds of other connections. It’s hard to describe Will’s role because he is in some ways I think sui generis in the field, and it’s in part just his very quick wit and ability to take a contrarian view that isn’t for the sake of being contrary. For a brief while, for example, the Hastings Center ran several articles that he was writing called “In Defense of...”, and it was like “In Defense of Lying”, things against the grain. A lot of people still think of that piece that he had in either Atlantic or Harper’s about the bioemporium and neomorts as a serious thing. It was Swiftian, it was totally Swiftian, but there were people who in later articles would refer to Gaylin’s proposal that we use neomorts. You don’t
804 get it!!

805 SWAZEY: It was a Swiftian parody but there are times now when it gets very scary.

806 CAPRON: Oh absolutely!

807 SWAZEY: Talk about prophetic!

808 CAPRON: That's right. I'm sure that I've been influenced through the years by Will's ideas.

809 In any case, a very influential group of people. Contrasting that to the Kennedy Institute....

811 SWAZEY: You spent time at Kennedy while you were at Georgetown?

812 CAPRON: Yes, though I was involved in a lot of things at the Kennedy Institute, a number of projects, before I was at Georgetown, but then when I was on the Georgetown faculty and was a fellow at Kennedy, I suppose I had that direct involvement.

815 There are several obvious differences between Hastings and Kennedy. One is being part of a university and specifically having your principal ties to people coming out of the philosophy department and/or the religion department. The other is the fact that for a long time the Kennedy Institute, it seemed to me, was mostly aimed at education; both educating people who wanted to take courses towards their degree at Georgetown, getting either an undergraduate degree or PhD, and their very, very influential intensive course, reaching a broad public of people who wanted to become more expert in the field. Then, later, they developed The Kennedy Institute of Ethics Journal, trying to reach to a broad
audience the way the Hastings Center had from the beginning with *The Hastings Center Report* and briefly *The Hastings Center Studies* and then the enlarged *Hastings Center Report* incorporating *The Studies*. The other obvious difference involves projects. There were projects developed by the Kennedy Institute, and I participated in a couple of them. One I remember was on the issue of social science research, that drew scholars not only from Georgetown but from around the country. But Kennedy being an academic unit, I think, saw its faculty more as individuals, and the original funding, I guess, of some of those professorships was generous enough that the people in those positions had a good deal of time to write. Certainly it’s scholarly work was a pride of the Institute. You would go into the institute and the books, or the dust jackets of the books, were prominently displayed. Here’s everything Tom Beauchamp’s been writing and here’s everything Bob Veatch has been writing and so forth. So the emphasis was on a place where scholars in the field, whatever their particular individual background or take on things, were doing their work. They would get support from each other, intellectual support, but they were still individual scholars. Whereas the whole focus, at least in the early years of the Hastings Center, was of people coming from their institutions to Hastings and working collaboratively on projects. Sometimes writing papers which would be a book growing out of the project, but very often trying to meld something into a group statement. At least
that was principally true in the early years.

SWAZEY: One thing that has struck us is that there seems to be very little interchange or intercourse between the different bioethics centers and programs. Just based on your work at Hastings and Kennedy, was there much exchange?

CAPRON: Well, over the years Kennedy ended up with a number of people on its faculty who had had Hastings connections. Leon, of course, was briefly on the Kennedy faculty before he went to Chicago, and most prominently Bob Veatch. But I think it’s fair to say that there wasn’t, on an institutional level, and even today there is not that much interchange. If you look around the country, I think Hastings has had a major effect to the extent that a number of its alumni are now in positions where they either run centers, the way Tom Murray does, or they have programs but not centers, like Ruth Macklin does. Particularly because when I say “alumni” I mean former staff members, since Hastings doesn’t have graduate programs. In the early days of Hastings, of course, there were no other centers and people were coming to Hastings from their own involvement in their own field. I think the thing that’s changed so much about Hastings is the extent to which the research groups now are less chosen simply because people might have something interesting to say, whether or not they have any narrow background on the topic, and much more in kind of a correct fashion to make sure that if you’re talking about a given topic you have people from the relevant organizations and so
forth. It's a little more of a conservative kind of approach. It's very hard with any
organization to make judgments over time, because the perspective is so much
rooted to what the world is like at a particular time and you don't have an
objective view of things. I've heard from any number of people, including people
who have been very involved in Hastings over the years, that they don't have the
sense that the staff who are there now have the same stature as the people in the
early years...the early associates. I don't take quite that view myself. I think that,
if I can say something that won't be identified by name. When my former student
Susan Wolf, was hired by Hastings, about 10 or 15 years ago, Will or someone
said, "Oh now, Alex, this is not a person like so and so we had before." By the
time she left and then went on to Minnesota, not only was her leaving felt as a loss
at Hastings, but she had established herself and continues to do so. It may very
well therefore be that some of the young people on the staff there today are going
to be regarded 10 years from now as giants. It is true that some of the early people
in the field, particularly Bob and then later Ruth Macklin, who came on first as a
NEH fellow, and Art Caplan, are now major figures in bioethics, but that's
because they have been in the field for 20 or 25 years. But there is, I think, a
perception that there has been that change. I think that is one of the reasons why
there is less of a drive for people in different parts of the country now to think that
the way to work seriously on a topic is to be involved in the Hastings Center
group. So this really is, although it didn’t sound like it was going to be, a response to your question about that linkage. To the extent that Hastings really was the place that drew people together, people from Kennedy were involved as much as people from anywhere, but of course that involvement was secondary to whatever else they were doing as fellows or research group members. In the early days, if there was an academic center and a medical school that was close to Hastings it was Columbia, because of Will Gaylin’s involvement, and then Bob Veatch and other people doing some teaching there. But today, both Hastings alumni and other people have centers and programs in places like Minnesota, Wisconsin, Kansas City (the Midwest Bioethics Center), the group at Brown University, David Rothman’s group at Columbia, which is less a bioethics group, since its focus is more history and social science, Al Jonsen at the University of Washington. In some ways the Midwest Center is a better example of the non-academically based centers, many of which are very strong, like the Center for Health Care Ethics in the St. Joseph’s system here in Orange, California, and any number or other ones like that. Of course I should mention Mark Siegler’s group in Chicago. Mark is an example of someone who was an active participant in the early days of Hastings and who I don’t think is very active now; he usually comes to the Fellows’ meetings, but not always. Maybe I’m wrong, but I doubt he’s been on a research group there for years. He has a very active Center, which of course
has the very distinctive tone to it of being physician-oriented, the Clinical Medical
Ethics Center at the University of Chicago. There is so much activity at all of
these places now that in some ways I’m an oddity for continuing to be as active in
Hastings things as I have been; it’s kind of out of sentiment as much as anything.
In recent years it’s been much more as a member of the board and trying to help
shepherd the organization through its transitions than it has been for being on
research groups. The last three or four years I don’t think I’ve been on a research
group. I continue to write for the Center but it’s probably been that long since
I’ve been to regular research group meetings. So the brief answer is, there was
never any close relationship that I know of between Kennedy and Hastings
although they both started at more or less at the same time. Hastings just a little
bit earlier and both became, in effect, major forces in the field and sort of the
contrasting view of the independent versus the academically based.

SWAZEY: That strikes me as sort of generically true if you look at the different centers and
programs. I’m not aware of instances of collaborative work between centers or
programs saying, “We’re interested in this common set of issues, let’s do
intellectual work on it.” Everybody seems to work very hard at setting up their
own places and keeping them funded, which Lord knows is enough of a challenge,
but pretty much everybody’s in their own setting.

CAPRON: I think that’s true, though I’m sure that there are contrary examples. I have this
gnawing thought in the back of my head that there must be more than one
someplace. I think that is right for many of the academic centers, if their
experiences are at all like mine. Of all of them, I think Art Caplan’s is the only
one awash in money. Most of them, as you say, have such concerns about
keeping their own heads above water and they probably have enough difficulties
internally within their universities working out the byzantine financial
arrangements that are necessary to do interschool collaboration, getting people
from different faculties together for research, much less for teaching, that the
collaboration, when it occurs, probably occurs by bringing in individuals from
other places to be on your research project. I have done that here a good deal, for
example and had Dan Wikler, Norm Daniels, and any number of other people
involved in research projects. One thing that would be interesting to look at
would be whether the genome project has changed any of that, because certainly
when there is a good deal of federal support for something is exactly where you
expect to see inter-university or private groups and university groups working
together in the biomedical area. You get multi-center collaborative studies and so
forth. I wonder whether the genome area, which is the only example in recent
years of there being any substantial amounts of support for quote “bioethics
work,” led to very much inter-university work? You could check that.

SWAZEY: It is certainly something we can look at. Tell me a little bit about your Center.
Why you started it and how you characterize it.

CAPRON: I had been here for about five years or so and was working with colleagues in several different parts of the university, but principally with a couple of people in the medical school where I was doing teaching. The chair that lured me out here involves half of my time in the medical school and half in the law school. Along the way the Irvine Foundation got in touch and asked was there interest in work in ethical issues in medicine here at USC. The Irvine Foundation, as you may or may not know, is a very large California-based foundation coming out of the Irvine family, which owned huge pieces of Orange County and other places and other businesses. Stanford and USC were two of its principal beneficiaries in a pattern that involved, every other year, giving either Stanford or USC a couple of million dollars. The tradition had been that the money was, more or less, for whatever the university needed it for. So if you were in the middle of a building campaign and you needed a new parking garage, you’re not going to get donors who want to give that, but the Irvine Foundation money could be used for it, or some area of scholarly pursuit that doesn’t have a lot of financial appeal. The university had a lot of freedom, which was sort of understood; it was almost like a sinecure: Irvine will come through. Apparently, in the late 1980's the Foundation must’ve come to the conclusion that it wasn’t happy with this pattern, that it wanted to see the universities using the money in a more focused way, for things
the Foundation itself was interested in. At that point the Foundation apparently
thought it had some interest in the ethical issues in medicine. So we said, “Yes,
that might be something.” They said, “Well, let us give you a planning grant,
$50,000 or something, and you figure out what you can do here at the university.”
And so we retained a couple of people, one person on the university payroll
already, whose salary I partly paid, and, a colleague at Loyola Law School, Vicki
Michel, who I think, was feeling that she didn’t want to stay in law school
teaching. She had been active in the Bar’s Biomedical Ethics Committee and
knew a lot of people around town and was well acquainted with the issues. What
we did is sort of put out feelers everywhere to find out who had interest in
bioethics. It turned out there were a lot of people who had interest including other
people -- I keep coming back to this -- from the social sciences, psychology,
sociology, anthropology. Some people from medicine, a couple of people who
had some interest from philosophy but then disappeared. From public
administration, there was one person from business; there were people from the
Annenberg School of Communication, people from the School of Allied Health
Professions, particularly the occupational therapy department. We found that the
most time-efficient and best way to find out about interest was to have any two or
three people who were available for a couple of hours at any particular time come
and sit, very often in this very room, and each person spend a few minutes saying
what their research area was. Just in that process we found all sorts of people
who didn’t know that the other people existed at the university. They said, “Gee,
what you’re doing is very interesting to me because I looked at this from this
aspect, etc.” People were putting things together. And so when we were done, we
put together the proposal for the Center and we asked for it to be funded at $1.6
million over two or three years. Then Irvine made it very clear to us that they
liked the proposal. We met with Dennis Collins, who’s the president, and he told
us that the previous year they had been sitting down with Don Kennedy and
someone else from Stanford to talk. They said to them that they really wanted to
see developments from Stanford in our programmatic areas, and they talked about
what those areas were, and they said almost at the same meeting Stanford was
suddenly talking about how they could use the Irvine money to do this and this
and this, it all fit beautifully. They said they had the same conversations with the
vice president for development here, and it didn’t click. They just kept getting
this sense that the $2 million was for general support; they just weren’t getting
through. So we became the messengers and the message was, “they want to fund
us, and the reason they want to fund us is because we’re in their area and they
want you this year, when you put in for the money, to put it in as something that is
programmatic to their existing program.” So the university actually put together a
proposal that year, for more than $2 million dollars, that included our request.
Irvine apparently went to the vice president and said, "How do we know the university will continue to be interested in this when the money is gone?" And he suggested that we make it a matching grant, so USC can show you that we're interested. So Irvine came back and said, "Here's $800,000, and if you raise $900,000 in addition, you can have it. You get the first part without a match, and the next part one to one, and the next part on two to one." So over four or five years, rather than two or three years, we did raise the money and qualify. What we began with was one project which was very outward looking, and another which was very academic, combining the very kinds of things that we had hoped would come out of the deal. The outward looking project was...this was just at the time that Congress was passing the Patient Self-Determination Act. I had been an opponent of the act because I thought it was unlikely to succeed, particularly because of the way it was structured. But recognizing that it was passing, I figured we'd better do a good job of implementing it. I had already begun talking to people around the state to see that this or that chain, or this or that trade group, was going to try to come up with a way or implementing it for their group. I could just see a situation in which you went into one hospital and you got one bit of information which the state had said was okay, and then over here was a slightly different formulation of allegedly the same information. So I talked with the Commissioner of Health Services for the state and said, "Why don't we put
together a coalition, I’ll organize it if you’ll send your representatives and make a
good faith effort to have whatever we do be the state’s response to this federal
act,” because it was required that the state come up with approved language. I
also knew that if we left it to the state bureaucrats to write, it would be terrible
too. So we got the state, the Hospital Association, the Nursing Home Association,
the Nurses Association, the Chaplaincy Association, the Social Work Association,
Kaiser, and a couple of the other big providers of that sort, and the Bioethics
Center at Stanford, the bioethics group out of St. Joseph’s, and California Health
Decisions for the broad based consumers representative. Our Center organized it.
We were able, because of the funding we had from Irvine, to get that rolling very
fast.

SWAZEY: That’s where the PSDA Handbook came from.

CAPRON: That’s our effort here, the PSDA Handbook for each of the different categories of
institutions and then the approved language of the brochure, which took forever to
write. We worked very hard on it and got it down to the right grade level. I
continue to think it does a very nice job. I’ve just discovered that I have another
research project here because I don’t think it’s being used, despite the federal
requirements.

So that was the outward-reaching project. It was a very good launch for
the Center. The more academic one was the project that we put together just the
way we had been having those preparatory meetings where people talked. We realized there was a need to look at what happens when people from different ethnicities are confronted with the present day suppositions of the health care system, which is that the worst thing you can get is too much health care at the end of life. What you want to do is write out your instructions and bind your family, your representatives, and your physicians to your instructions.” Obviously that had arisen as an expression of the wishes of sort of the dominant culture, the well-insured, white, middle class population that had a certain kind of a relationship with physicians and hospitals, and a certain set of fears and expectations about what was going to happen at the end of life. But we live in this very multi-cultural city. I think Los Angeles is the single most diverse conglomeration of people who ever lived in one place, more so than New York at the turn of the century. There are so many more cultures and races and ethnic backgrounds here right now. So the groups that we had seen around the table started off and there was an anthropologist who was interested, and a psychologist, and a physician, a statistician and so forth. Then we brought in Leslie Blackhall, who is a physician with a masters degree in theological studies and bioethics from Harvard, who took the lead as the principal investigator. And we got funding from the Agency for Health Care Policy and Research to carry on that study. I think it’s one of the several more empirically-oriented studies that
has marked our Center from others. The project that I’m desperate to get funded now is to try to find out what kinds of moral obligations people think are relevant in making decisions whether to undergo genetic screening for adult onset disease, where the susceptibility might be there for cancer or something because of their relationship with their spouse, their children, their siblings, or their employer for that matter. And to re-frame and get away from a rights orientation, but also explicitly recognize that the context of the disease and the severity and the preventability will all probably affect how people regard whether or not they feel some obligations. That would be very important for genetic counselors and physicians to know because, people come to these things and say, “I’ve never faced this before, how do I decide?” One of the ways of helping them to decide is to situate it in terms of socially accepted norms and so forth. Also, the legislators are pushing legislation that relates to these kinds of issues, and they can either just shoot from the hip or look to public opinion polls, which are pretty shallow and often when they deal with a topic that people aren’t familiar with, doesn’t have a lot of salience yet for them, are likely not to be very informative.

So would you say that the kind of research your Center is doing is a hallmark that makes it very different from most of the others?

I think so. The other hallmark is that we have no university funding (laughter).
universities and also even at Case Western, do have some central core university funding. But the social science empirical side is a major thing here. The counter side to that is the fact that my co-director is a physician and I’m a lawyer and we don’t have the philosophers. There have been a number of people from the religion department who have taught courses with us but not from philosophy.

SWAZEY: Were you surprised by the disinterest of the people in the philosophy group?

CAPRON: No. Philosophy is a department that’s gone through an interesting cycle in the time I’ve been here. They really built up a good deal, mostly by hiring a couple of people who I think had not shot off the charts in their first few years in teaching but who turned out to be fabulous scholars. Those people in the last couple of years have been lured away, unfortunately. But the department’s interests just have never been on the applied side. The funny thing is that their biggest complaint as a department right now, I think in part because of their decline in their ability to get the very best graduate students because they’ve lost several of their bigger stars, is that they’re being pressed to be more of a service department for the university, which has put in a big core curriculum for the undergraduates. They have some fancy name for it, but it’s basically a re-introduction of the basic liberal arts and obviously good courses in philosophy make a lot of sense as keystones to that.

CAPRON: The philosophers don’t have the luxury of saying, “Sure, let’s devote some time to
this.” But the ironic thing is that this could be a field, I think, where they could find a market, as it were. The dean asked me, in part, when they were doing all sorts of things to keep me here instead of going to be dean of the law school at Vanderbilt a few years ago, “What do you want?”, expecting me to ask for more salary. I said, “What I really would like is for the philosophy department to have authorization to hire someone in applied ethics.” He said, “Oh yes, we’ll give it to them.” They’ve had it for two years and they haven’t hired anybody. They all keep giving me the reasons that they don’t find the right person.

SWAZY: Is bioethics taught anywhere in the curriculum here?

CAPRON: Bioethics was taught, I guess still is taught, to undergraduates in several places in the curriculum, mostly growing out of the school of religion, which is really a department. It has been called a school of religion because they had a program in social ethics, but they have just decided to close that program. So they will probably continue to give a couple of undergraduate courses in bioethics but they won’t have a graduate program there, which enriched the things that they could offer. What I thought would be a reasonable building block for a program explicitly in bioethics would be to use a lot of those courses, and some from public administration and law plus some clinical exposure. But we have sort of stalled on that curricular side. I think we have, for the medical students, one of the more extensive programs, outside of the kinds of places like Galveston and
Hershey that have this very big humanities apparatus. When you talk about Kennedy and Hastings, the third leg of the stool in the early days was the new Penn State Medical School at Hershey and then a little bit later the Galveston program, which were a different approach. Hastings really is bioethics in the sense of multi-disciplinary people coming together, bringing their disciplines, bringing some of their own work in terms of giving papers in their own field, but trying to work collaboratively on joint projects. Kennedy is individual scholars, principally out of philosophy and religion but a little bit broader, working as individuals without a huge teaching program. It wasn’t as though they were running graduate students through there by the dozen or something. Then the third leg, the third model, is the more humanities, history, literature, economics, psychology approach of the Hershey program headed by Dan Clouser and the Galveston program, based in a medical school, which Kennedy never was. In fact, when there was some falling out at Kennedy, it was Ed Pellegrino who went over, right at Georgetown, and set up another bioethics institute in the medical school with Warren Reich. Warren was still at Kennedy, but I think some of that moved over to the clinical side, something closer to what Mark Siegler does in the medical school at Chicago but bringing in disciplines, in addition to philosophy. At USC we have a curriculum which includes a couple of exposures in the first year to lectures and then to a half day case-based experience in small groups of 6
to 12. We've used things like *Dax's Case*, the video about the burn patient. In
the last couple of years we've used the letter, "It's Over, Debby," and set it up
initially as a drama with someone being the person who wrote the letter going
before the chief of staff and being interrogated about it. We have the students
role playing hospital administrator, and chaplain, and head of nursing, and head of
medicine, and so forth, and a member of the ethics committee deciding what kind
of policy the hospital should have in response to this kind of a revelation. At the
current time, we don't have anything in the second year except voluntary
activities. In the third year we've now got most everything. One of the courses
had been in the fourth year and we moved it back to the third year to give us more
time. We have a rotation through general internal medicine during their clinical
rotation, the first time they're there, and they're given a six-week course. When I
teach it with David Goldstein we assign groups of about 20 students, into teams,
so that each week there is a team of 4, except the first week where we run things.
They bring forward a case which embodies an issue that they want to talk about,
whether it's consent, or placebos, or confidentiality, or whatever. One of them
will talk about the issue, having researched it. One of them will present the case.
Then the other two will argue either side of what should happen in this case.
Coming down from the general principles about, say, a placebo. For example,
what is a placebo? What is the theory about why it works, or what it means, or
what it shows you? Arguing, for example, should you or should you not give a
narcotic for pain control to a patient who’s come in claiming pain from
pancreatitis but who’s a drug abuser and who you think is there to get
drugs...arguing back and forth on that. One of the main things I hope they get out
of it, besides learning a little bit about the particular topics that we deal with, is to
have them experience the process in which people who you respect are arguing for
a position that you find difficult to accept initially. Sometimes the position is
such that even the person who’s been assigned that role almost signals to the
class, “I’m being devil’s advocate.” Virtually uniformly they do a very credible
job of putting forward the arguments in favor of that position, whatever it is. I
hope it makes them stop and think the next time they’re in a real clinical situation
and someone is arguing something that initially strikes them as wrong, whether
it’s on a technical question or one of these ethics questions. Hopefully, they don’t
just dismiss it and say, “What a jerk! He doesn’t know what he’s talking about!”
Instead, they stop and they think, “wait a second, there are arguments that can be
made on that side and I’ve got to be prepared to think them through and have a
rational response, not just a gut response.”

The second third year course we have is a selective, where they chose
among art in medicine, literature in medicine, economics in medicine. It’s a six-
week rotation, and is a book-oriented, sit-down classroom course for only a
couple hours per week. The big course that they have is called The Physician in
Society, and it’s now half-days for a month. We go over the whole health care
system, the financing of health care, the issues in research, the issues in clinical
choice like formularies and HMO formularies, questions of policy for hospitals,
how to deal with issues of AIDS, issues of drug companies handing out free
supplies, funding things, just a whole wealth of things. The students have small
group projects which they then report on to the whole group, coming up with a
policy on one of these current contentious topics. I think it’s one of the more
extensive curriculums, and our Center is responsible for that. So that’s the other
main thing that we do here.

SWAZEY: Let me jump back in time now, from the Pacific Center to “Alex goes to
Washington” on the President’s Commission. Who and what got you to that job?
CAPRON: Well, I got the job because Morris Abrahm called me up and persuaded me to take
it.

SWAZEY: Had you known him?
CAPRON: I had not known him. Morris knew Will; they were both on the board of the Field
Foundation. You know some of the history of this with the National Commission
coming into place in 1974, and for that one my involvement was as a consultant. I
wrote for them on their first project but was not otherwise that involved in what
the National Commission did. When the authorizing legislation was running out
in 1978 and Ted Kennedy was trying to extend it and make it a Presidential
Commission rather than a commission appointed by the Secretary of Health,
additional issues. One of the people who, early on after the statute was passed,
got interested in it was Morris because of his own well-publicized bout with
leukemia. He otherwise didn’t have any particular background, other than the fact
that he was a Georgia Democrat originally, who had defended Jimmy Carter to his
New York Jewish friends. Morris was then, or had been, head of the American
Jewish Committee and very prominent. He had that brief period as President of
Brandeis, the first president after the founding president. So he was a very
important figure and for him to basically say, “As a fellow Georgian I can vouch
for you that Jimmy Carter is okay” helped allay the fear of a southern Baptist.
That meant that he was close with the White House, and when the President’s
Commission came along I gather he basically signaled that it interested him. It
didn’t interest Jimmy Carter very much because it was sponsored by Ted
Kennedy, who was then beginning his opposition to Carter’s having the
Democratic nomination in 1980. So it took the President and the people in the
White House quite a while to get around to officially naming the Commission and
then figuring out where the money was going to come from. I guess it would have
been in the early fall of 1979, he was still trying to figure out how they were going
to reprogram money that had gone elsewhere to provide funding for the first year of the Commission. Beginning in September of 1979, the commissioners like Renée and others had been named but hadn’t been sworn in or anything. Morris got in touch with me after asking Will, “Who should direct this Commission?” Will said, “Well, there’s only one person.” Will probably gave Morris a list of ten, but he always tells it, “There’s only one person but you won’t be able to get him, that’s Alex Capron.” So Morris called me up and I indeed first said to him, “I am very happy here at Penn. We’ve just renovated a house, and I have no desire to move to Washington.” Morris said, “Come on up to New York and see me, I’d like to talk to you. Just tell me what you think about the field.” So I went up and after doing that a couple of times, he had basically persuaded me that I wanted to do it. And he did it most directly simply by saying, “I don’t know this field, you do. I’ll let you run the thing. I’m not going to be interfering, I’m just going to be supporting.” And he said, “I have my views on things but....” Unlike many times where I suppose a commission on XYZ is appointed, the person who is appointed chairman of it, like the Challenger Rocket Commission or the Space Shuttle Challenger Shuttle, knows a lot about the field. The person brought on as a staff director is there to facilitate things, but Morris said “All the hiring decisions will be yours...”, which was mostly true. There were a couple of people there, a secretary and a person who was supposed to be the deputy director doing
administrative stuff, who didn’t work out very well. She was gone after about a
year. But yes, I had a totally free hand.

SWAZEY: Is that what convinced you to take the job?

CAPRON: Well, that and the substance. The substance was interesting. As Morris said to
me, “The topics that have been written into this bill by Congress read like your
curriculum vita. You’ve written on all of these things. So this has got to interest
you. If you have the opportunity to write for a broader audience with the
imprimatur of a Presidential Commission, why don’t you do it?” One of the
things that made it difficult to do it was that Jay and I were then at work on
another book, to be a casebook on informed consent. I was on sabbatical that fall
and was going to be working on it, which was another one of the reasons I first
gave Morris why I wouldn’t take the job. Jay was initially very unhappy. We
didn’t have a falling out over it, but I said, “I really think I’m going to do this and
I know that it is going to slow down or interfere, but I’ll continue to try to do it.”
But he knew that wasn’t really possible. A couple of months later when I was
talking to him he said, “I didn’t understand that you were going to be the director,
I thought you were going to go as legal counsel to some group. Now I understand
why you wanted to do it!” After that he was much more understanding about it.
So I commuted to Washington that fall and had things set up for the
commissioners to get sworn in at the White House in January of 1980. Then, for
the very reason that Morris was able to get me, I was able to turn around and draw
certain of the key staff positions from people in academia who we borrowed for a
year from their universities. And several of the people that I hired were people
who had some experience with the National Commission. Barbara Mishkin
principally, who worked with you a lot on the Whistleblowing Project. Others
were serendipity. Andy Burness, who has gone on to a superb career, was then a
Hill staffer with no particular background. He'd been involved with the college
newspaper down in North Carolina at Duke, but didn't have any particular
background in public information, and turned out to be just wonderful. And now
his whole career in public information is around these fields. Renie Shapiro,
whose background was in public health and epidemiology, worked a lot with me
on the genetic reports because there was no one else on the staff to really do that.
She helped develop that and went on to do all sorts of things, most recently be the
chief speech writer for Kessler when he was FDA Commissioner. The one person
with a connection to Renée was one of those undergraduates who she had gotten
into my course years before, Jeff Stryker, who I think had gone through Penn in
three years or something. A very bright guy. Renée said, "You've got to have
him in your bioethics class." He showed up on my doorstep when I was first
staffing the commission. He had gone for a year, perhaps less, to Rutgers Law
School at Camden after he graduated from Penn. But being very young and sort
of one of these people who got ahead of himself a little bit, he found that for the
first time he really wasn't doing the right thing. He had been sort of knocking
around doing various things for a few years. He was just a wonderful staff
member, sort of the research assistant, but invaluable. He also has gone on to a
career in the field. The other person, who was not serendipity because I was
looking for and interviewed a number of people including some much more senior
people, was Joanne Lynn. The other physicians I had been looking for and
interviewing were people who brought a lot more scientific background. She was
basically a clinician at that time and working in the beginnings of the hospice field
with nursing home patients. I guess she was already taking a graduate program at
George Washington. She has just become one of the most important figures now,
in part because of her empirical work but also broadly in the end-of-life area. I
had been thinking of someone who would work on that but would also have
worked on the "Access to Health Care Report," which she did a little bit. But her
major commission work was on the informed consent and particularly the end of
life reports. The others, as I said, besides some people drawn for secretarial and
support positions from within Washington, were mostly the academics. They
were people who all had solid positions but I think this sort of elevated them in
the field. The reputations of people like the two Dans, Dan Wikler and Dan
Brock, and the two Alans, Alan Meisel and Alan Weisbard.
SWAZEY: It made things simpler, if you just yelled out a name someone would answer!

CAPRON: We decided we weren’t going to have the position of “staff philosopher,” we were going to have just “Dan.” In the end we had Allen Buchanan as well as the third philosopher, and that was confusing because the “Alan” was otherwise the attorney, first Alan Weisbard, then Alan Meisel. Mostly it was just an extraordinary collection. And yet at the beginning, when you looked at those people their resumes didn’t yet say, for the most part, this is going to be an extraordinary collection of people all of whom are going to go on and be solid, top-level figures of what you’re calling this middle generation in bioethics.

SWAZEY: What were your expectations when you started the commission about what you would accomplish and what the commission would accomplish?

CAPRON: I suppose they were mostly framed in terms of what the National Commission had done, and they were partly framed in reaction to what the National Commission had done. The National Commission, by its statute and its charter, had two tasks and it had really ended up addressing only one of them, which I think was inevitable. The two tasks were the ones that grew out of the experimentation topic that really provoked the hearings and the legislation, and the one that had been lying around since the late 1960's that Walter Mondale had a pretty strong interest in, about the broader questions of the impact of developments in medicine. He and others had held hearings with Josh Lederberg on genetics and
some of the early discussion of cloning and the like. That, which they ended up
calling the “Special Scholarly Study,” didn’t go anywhere.

SWAZEY: Yes, I was on that too committee; I pull it out every once in a while and think,
gee, a lot of work went into that!

CAPRON: Right, and I think they ended up using a delphi method, didn’t they?

SWAZEY: One part of it was.

CAPRON: I remember being one of the Delphi study recipients. I guess it was my other
involvement with the National Commission, besides writing the piece on fetal
research.

SWAZEY: Delphi studies have never impressed me; Herman Kahn’s forecasting was always
so awful. I thought that was a huge waste of time and money; it was really
expensive.

CAPRON: Yes, a lot of people collecting a lot of information. Anyway, the National
Commission’s major impact had been the human subjects research topic. And
because of the history of that research the Department itself had been trying to
scramble to stay ahead of the legislation and had come out with its first set of real
regulations right as the National Commission was starting. I remember being at
the Cosmos Club at this sort of rump session that Charles Lowe had. He ended up
as the short-lived first director of the Commission, because he was basically
trying to do with the Commission what he had already done through this rump
process of getting together a group of us from in and outside government and
meeting at the Cosmos Club. I guess his argument was is that we were not a
committee, we were just a group of consultants who happened to be in the same
room at the same time, just coincidentally.

SWAZEY: Otherwise it would had to have been a pre-announced meeting.

CAPRON: It would've had to have been a pre-announced Federal Advisory Committees Act
thing. Instead, he was just trying to get us to come up with the framework for the
regulations so that they could go to Congress and say, “We don’t need your
commission, thank you very much. We don’t need that process, we really are on
top of it and here are the regulations for different subjects.”

SWAZEY: I gather they fought very hard to forestall the Commission.

CAPRON: Absolutely, and this was a big part of that. I’m sure that Charlie McCarthy and
others whom I’m sure you’re talking to, can give you in detail the ins and outs.

So I saw the National Commission, as just by force of history and its charter,
being kind of pushed into coming up with what were quasi-regulatory responses.

They didn’t end up writing the regulatory language but they wrote what became
the framework for the regulatory language. All that was very useful; it was useful
to examine the special issues with fetuses, and women, and prisoners, and
children, and the like. And then of course the enormously influential Belmont
Report, which is either the statement of what was all along their collectively
understood framework, or was something which was pulled together at the end to explain what had happened and to abstract from it the basic principles. I think people have different views as to whether you should regard it as deductive or inductive. But the “Belmont Report”, is the document that people constantly return to, in part because of Tom Beauchamp’s involvement with it’s drafting. And then Beauchamp’s book with Childress, which takes more or less the same principlist framework and adds a fourth and makes it a huge book. Well, not a huge book, but compared to the Belmont Report, which is just a few pages, a very elaborated explanation of the principles and their application that has been enormously influential.

I thought the President’s Commission had the opportunity, because our topics were so much more diverse, to look with each topic to different audiences. I had one caveat that for every report: I felt the public through the press was to be our audience. That is to say, we should write something that someone could read about and say, “Gee, I’d like to know more about that,” and get ahold of the report and read it. It should be in every federal depository library, it should be published in a format that made it look like a book and not like a report, with some graphics to make it slightly more interesting. I really started off very clearly saying, “how do you avoid ending up producing something that is filed in a few people’s offices, and instead really has an influence?” Part of the reason the Commission
succeeded was, again, serendipity...I mean truly just serendipity. Morris and I had agreed our first report ought to be the “Determination of Death Report” because it was a topic that was the easiest to get our hands around. Not only was it one that I had worked on forever, but it lent itself both to something that people could find useful, namely a statute, and something where we were very likely to be able to sum up a topic that had already had a lot of thought from a lot of people, and where a basic consensus existed. And it was still valuable to pull the consensus together and show what its practical application was, but it wasn’t something where we were going to have to spend years and years getting people to agree. It still turned out to be a hell of a lot of work, particularly, for example, getting all those medical people to come together on the separate but connected consultant’s report that was published in JAMA with the actual clinical tests and criteria for the determination of death. We had a meeting out at Airlie House in August 1981 to have the commissioners say “Aye” to the final draft, having seen a number of iterations. It happened that on that day hearings were being held in the Senate on the Human Life Amendment. And so The Washington Post, that day, and all the major papers the next day, had us on the front page with either an article or side by side articles; the basic gist of which was: Congress debates when life begins, Presidential Commission debates when life ends.

In our work we were talking about how you measure the cessation of the
relevant biological functions. We weren’t defining in some cosmic sense, this
wasn’t a definition of death, it was a determination that death had occurred. But I
wasn’t about to argue with that interpretation in the headlines. And the staffers at
Nightline, which was then only just beginning to move beyond “America Held
Hostage” and onto these broader topics, loved this juxtaposition. And thank God
they didn’t directly try to juxtapose the two; they just said, “Well, this
determination of death issue is interesting.” And so one of the Commissioners,
Don Medearis, a physician, and I got whisked off that evening to Washington.
The hardest thing about that program was they had spent all day calling me. I had
to keep running out to the phone because they said, “We can’t find anybody to
disagree with you. Who disagrees with you?” And I said, “That’s the point!”
Although it’s still somewhat unfamiliar to the average person, this is something
about which people who’ve thought about it from law, philosophy, medicine,
nursing, don’t disagree. Who they finally found was a right-to-life person,
actually very good for their demographics, a black woman physician from Boston.

SWAZEY: Mildred Jefferson.

CAPRON: Exactly. Who of course, had never read the report, didn’t know what the report
said, but as a right-to-life person was able to come at it because we were saying
that you should pull the plug on a dead body. She was prepared to say that was
just like killing a fetus, and so it was wrong. So they had her on, and they also
managed to run footage of some hospital in western Massachusetts that
specialized in PVS patients and gave them intensive therapy. A few of them, of
course, those who probably weren’t in a PVS but were brain damaged but
recoverable, recovered. I think instead of opening with that, they showed it that
after we had been on. We were just seeing it, as we watched the show. The basic
point it tried to make was that the Commission is saying that these people should
be called dead, or something. And that wasn’t what we were talking about at all.
The next night Ted Kopel ran an apology. But none of that is as important as the
fact that it launched the Commission and gave us huge visibility and greatly
increased the fact that from then on we always had the print media, and most of
the time, television cameras, there for our meetings. That elevated in the
Commissioners’ own eyes the fact that what they were doing was going to have
public impact.

SWAZY: What sort of social circles connections did you have as you moved around
Washington in that job? Did you connect a lot with people like Ted Kennedy and
Al Gore, who were interested in these issues?

CAPRON: Yes, but of course what happened just...we began in January of 1980 and in
November of 1980 there was this cataclysm in national politics. It was a
cataclysm which didn’t affect us as you might otherwise have expected. As you
may know, during 1980 Morris Abram got fed up with Jimmy Carter mostly
around the policies on Israel and came out for Ronald Reagan. (Laughter) So here

was a democrat who had been a vocal and visible supporter of the President now

not being a supporter of the President. So when the Reaganauts from the new

administration....

SWAZEY: Not showing any political biases! (Laughter)

CAPRON: Well, I’m sure it’s true anytime, that the transition teams come in with a total

suspicion of anyone who’s already anywhere in the government.

SWAZEY: I do remember, with all facetiousness aside, that commissioners during the

second part of the Commission had a different cast.

CAPRON: But we weren’t even to that point. The real question was, was this commission

going to go on at all? Were we somehow part of some democratic cabal doing

bad things to whatever we were dealing with? I suppose I could’ve made a

credible case that we were actually totally apolitical and that the determination of

death was not a part of some political agenda. Of course there was one hidden

part of the access to health care topic, but genetics is not a part of some political

issue. And we weren’t dealing with abortion, thank you very much! Reagan

always appealed to the right-to-life people but he never really did much about it; I

think his own history will say that. It wasn’t a major concern because we weren’t

dealing with it anyway. So I think I could’ve made that case, but the reason the

case carried with those people was that the Chairman of the Commission was
Morris Abram! He was someone whom they believed in and trusted, and had the ear of the top people on the transition team in the White House. So we just kept on doing our work.

At the very beginning of the Commission we had lost one commissioner, Pat King, because she went off to be Deputy Assistant to the Attorney General in the civil rights division, of the Justice Department and the statute said you couldn’t have anyone with a government position. We also lost Fritz Redlich, the former Dean of Yale Medical School because, although he was a faculty member at UCLA, his primary paid position was as director of the medical service of the West LA VA Hospital and so he was a federal employee. I remember having to be the one who told him, “Fritz, we’ve got to ask you....” He came to one meeting and got sworn in and then I had to call him up and say they’ve made a mistake. Don’t kill the messenger, please! It’s not my doing, if these people can’t read a statute and their background checking is so bad. So he was replaced very early on and then Pat King was replaced. Actually one of the good things about that was simply that we got a nurse in the process, and if you are going to deal with health care issues it’s odd not to have anyone from nursing.

Most of the people on the Commission, the early group of commissioners, had background in their field. Someone like Don Medearis, former medical school dean and distinguished pediatrician, Harvard professor, and so forth, was a
wonderful commissioner even though I don’t think he had ever particularly
written anything about medical ethics, or been on programs about medical ethics
or bioethics.

SWAZEY: He was a very thoughtful, concerned man.

CAPRON: Exactly! There was no one I liked better on the Commission. When the National
Commission was appointed there were relatively few people you could think of
appointing who would’ve had a background in bioethics. There were plenty to fill
a commission, but it’s not surprising that a lot of the people were there, like Ken
Ryan, as a distinguished physician and researcher. But given the fact that the field
was no longer in its infancy, it was perhaps more remarkable when you had the
Presidents’s Commission appointed across so many issues that it had relatively
few people, as I say, about four or five of the eleven, with any real background in
bioethics.

SWAZEY: Did you see that as a strength?

CAPRON: I just thought of it as a given, I didn’t think of it as a strength or a weakness. I
guess initially I would’ve been more delighted with more people like Al and
Renée who knew the field. But just as bioethics itself brings different
perspectives from the disciplines, the fact was that the Commissioners were
people with a whole lot of different experiences. Charles Walker from Tennessee
was a person who was just an ordinary “Doc,” and we needed, in the end, that
kind of perspective. Also, as an African American with an African-American patient population, he could speak with authority when we got to questions of access to health care in a way that a person who disagreed with him couldn’t just dismiss. So in the end I think it was a strength to have that diversity and that this was not to be a commission that was like just another academic group. And certainly it was true the fact that Morris didn’t have a bioethics background was no problem at all. I think that what Harold Shapiro brings to the NBAC is the ability to be a very good chair and to know how to keep a group focused and how to bring about a consensus. Morris is a past master at that. And then in his case, the direct access, first to the Carter White House and then the Reagan White House made things logistically easier.

You asked me about the other circles. We dealt a little bit with the Office of Science and Technology Policy. I had, through other connections with the Institute of Medicine and some scientific friends, some slight acquaintance with Frank Press, who was a friend of my then father-in-law. It happened that the person who was our budget examiner, Lynn Etheridge at OMB, was someone I knew from college. I had known Kennedy and his staff for a long time and had testified a couple of times before them at the time of the 1974 Act and on one other occasion for something else, I can’t remember what it was.

SWAZEY: That was during the National Commission days mostly?
Yes, I had known him since the early 1970's to that the extent that he would recognize me, and I certainly knew his staff to talk to. Gore is someone with whom I developed a close working relationship but only after the Commission had been well at work on its topics. It was particularly, of course, the work we did on the “Splicing Life” report the recombinant DNA genetic engineering as applied to human beings, that cemented that relationship because he took a great interest in it and decided that we should release the report in front of his science subcommittee of the House oversight committee for government operations. That of course, proved to be a great launching pad for that report and got it a lot more attention. He held three solid days of hearings and we were the lead off and so everything was sort of framed around our report.

Were the Shrivers still interested?

Yes, and on one occasion I met with Sarge and Eunice about what we were doing on the research side. It may have been that the Senator said, when some issue was coming up, “You should talk with my sister about that.” I think that was probably what it was. I don’t remember the exact details, but it was around the research issues.

It’s been a very constant cast of characters, hasn’t it?

On the highest levels, yes. Principally because of Rosemary Kennedy, the family’s interest and involvement has been pretty constant. I’m trying to think if
there were any particularly strong connections through people at the Kennedy Institute; I don’t actually think there were. It wasn’t as though there weren’t social connections and I’m sure we commissioned one or two papers from Tom or LeRoy or Bob. I resigned from the Hastings Board because I didn’t want to have any conflict there. The main connection we had with Hastings during that period was through my going to Maggie Mahoney at Commonwealth to raise some money to support interns. I figured the Commission should be used to do some educational work, and it would be good to have some extra summer help. I knew there would be people who would be interested in that and we didn’t have any money in our budget for it. It’s very hard to pay for interns in Washington; everybody is expected to do it for free. But I wanted to be able to be a little more selective than just having the people who were well enough off that they could work for nothing. I discovered that the government can’t accept money from people (laughter). The Commonwealth Fund can’t give money to the government. So we worked out a deal that she would make the grant to the Hastings Center and the Hastings Center would pay the interns their stipends to be Commonwealth Fellows at the President’s Commission. So that was a little behind the scenes maneuvering. But other than maybe somebody on the Hastings staff having been one of the people we hired to do a paper or something, we had no other connection.
SWAZEY: One thing I wanted to ask you about, which I might as well do it in this context, is the Access to Health Care Report. It's an important question so I'm going to ask it one part at a time. Renée's recollection is that you were largely responsible for getting that secured as a report that would be done because there was some discussion as to whether access to health care is an ethical issue.

CAPRON: I think there was some discussion as to how it fit as a bioethics issue. And I think it is true that it hadn't gotten the kind of attention that the more clinical issues, both those that are technically oriented like genetics and those that are sort of systemic issues like informed consent, had gotten. Once again there was a little bit of serendipity. The person I happened to hire as the lead staff person, for the access study was Susan Morgan, a health economist/public health person. Well, it happens that Susan’s family and Morris’ family were old friends in Georgia and because of that Susan knew Morris somewhat, and just had that slight credibility that kind of personal connection can bring. I think Morris recognized that the topic was going to be one that more than anything else we did could draw political heat. Susan’s politics and Morris’ were not exactly coincident. Morris by then was beginning to get somewhat more conservative on some of the social issues, or he was standing still and the world was moving, I'm never sure which it is with those kinds of things. And Susan was very much on the “the poor don’t have access to health care. It's a scandal. Ten counties in Alabama don’t have a single
obstetrician who will treat poor women.” I think Morris just had a greater comfort factor than he would’ve with someone else who would’ve been raising those same issues but without her family background. And so any inclination to say, “Well, we shouldn’t do a separate report on this,” or “this isn’t something on which you can do ethics,” he was very persuadable that that wasn’t the case. The actual statistics in that report are now, of course, completely dated although still lamentably very true in terms of the then 10-12% and now, whatever it is, 15-18% of the population who don’t have secure access to health care. What is important about the report is the philosophical case it builds for a notion of an obligation to insure access to adequate medical care for all.

SWAZEY: Was that report in your mandate?

CAPRON: Yes, it was. The ones that were generated by the Commission that were not in the mandate were the genetic engineering report and the care at the end of life, report “Deciding to Forego Life Sustaining Treatment.” So Renée is right, we had to push for the desirability of having the access report...we had to push for it twice. Once in the initial days of the Commission where the question was: can we do an ethics report on this? And that’s why I wanted to say that I think the ethics part of it is what has survived and is a contribution to the field. One thing that Morris was quite strong on and that made a lot of sense to me was that it didn’t make a lot of sense to write a report saying that so and so has a right to health care when
the Supreme Court has said there is no constitutional right and therefore the rights
you would be talking about would all be statutory rights. What you need to do is
build a case as to why the statutes and the organization of the administrative
system should be such that there is access to health care. So you have to build the
ethical case, and those arguments about rights end up being arguments about
rights instead of about the specifics of the situation you’re talking about. We
could find ourselves drawn into that debate endlessly and not productively. We
wouldn’t contribute anything to that debate, it would just be purely politics. There
were those both inside and outside the Commission who initially and maybe to
this day; people like Ron Bayer, were disappointed with our position and thought
that was a way of avoiding the real issue. “Are you going to say people have a
right to health care or not?” I continue to be of the view that if we had written
solely about the right to health care our report would’ve been much more quickly
forgotten. Just to give you an anecdote about that, about a year or so after the
Commission ended I was down in Nashville for a meeting at Vanderbilt and was
riding over to the meeting from the hotel with Uwe Reinhart, whom I didn’t know
at the time. I don’t think I’d ever met Uwe. And he said, “Oh, you’re Alex
Capron, you directed that Commission. I just read your report. This is amazing!
I’ve never seen anyone make out this case before. This is wonderful!” Uwe is
very strong on our having a much better health care system than we do now. He
said, "This is so valuable. This way of looking at it is so helpful!" At the time, because we had spent a fair amount of time with the editorial boards of the papers like *The Post* and *The New York Times*, I was particularly sensitive when they began talking about the obligation to insure access to an adequate level of care for all, which was our language. And that began being picked up. About four or five years later it was just the usual routine, sort of the base starting line. By the time we got to Clinton's health care plan, the editorials and the commentators and the Uwe Reinharts were saying, "Well, that's the obvious point, now the question is, how do we get there?" But that bedrock, that there is truly that obligation to insure access, we weren't the first people to talk about that obligation. Some people had talked about it in other ways, at other times, going back to the Truman Commission. I do think it made a contribution and it gave a solid foundation at the time. It reached out to people who were looking at the report because it was, in effect, about health care and economics as well; it had a lot of details about the organization of the system and about the holes in the system and so forth.

But one thing that's fascinated us is thinking about what bioethics has and hasn't focused on for thirty years.

It hasn't come back to that issue a lot.

It hasn't come back to it. I keep thinking of Dan's term, certain things have been "deselected". Whether it's because bioethics has focused so on individual issues
and rights and economy and so forth. But I remember Paul Ramsey saying early
on that the larger issues like social justice and health care seem intractable to
moral reasoning, which strikes me...Lord knows I wouldn’t denigrate Paul
Ramsey...as sort of a moral cop out. And I don’t think in the attention that
bioethics is now paying to managed care...they’re still not dealing with social
justice, the Norm Daniels’ types of issues. Norm’s sort of been a voice in the
wilderness.

CAPRON: Right. Norm was actually very helpful to us. For the access report we assembled
a group of philosophers which included Norm and Allen Buchanan and Dan
Brock, who were not yet on staff; this was when Dan Wikler was starting things.
The group also included several other philosophers who hadn’t been bioethics
philosophers up until that time; a couple of them still aren’t. We had them write
about these social justice issues, and how those can be understood. Just to
continue on this access thing, I think you were quite right that the topic as such in
bioethics circles has not generated the same continuing interest that goes to the
reproductive issues and the genetic issues and so forth. But each of our reports
ended up having an audience, and the audience for the access report turned out, in
my view, to be very often the health decisions groups. The health decisions
movement, which began in Oregon, came out of the clinical and particularly the
end of life issues. It was originally the work that we had done on deciding to
forego treatment that led to my involvement there. When Oregon Health
Decisions held its first meeting to get itself organized Ralph Crawshaw, who was
its moving force, called me up and asked if I would come out and be their keynote
speaker. He was going to arrange all this by having me also speak to the City
Club in Portland. And I was to talk about these end of life issues. I said I would
be happy to do it, and that was their initial focus. But as those groups got going, I
think very naturally, they began to ask the questions about all these extensive
resources being used at the end of life and seeing that was probably a
misapplication of resources. The next time I went back to Oregon, and when I
was speaking with California Health Decisions when they first got organized, the
report that they were then looking at and began to use was the access report. I've
always been a fan of what Oregon ended up doing; there are a lot of problems
because it is a sub-slice of the Medicaid population and that makes it very
problematic. They began to ask more broadly: "Well, who has access to these
resources anyway?"

SWAZEY: They took on a hard one and they tried and they did something.
CAPRON: Absolutely, and they did it explicitly and above board.

SWAZEY: They didn't use the green screen.

CAPRON: No, exactly. And so the notion that that issue hasn't gotten the Hastings Center,
a lot of meetings on access to health care, doesn’t mean that the issue hasn’t
gotten continued ethical thought, and I would say the Oregon advancement in the
ethical thought. I mean you go from saying, “Okay, again, we say there should be
guaranteed access to an adequate level of health care. Now how do we figure out
what that is?” We had some language about the different places you would look
and how you would conceptualize that term. It didn’t just mean basic health care,
it meant an adequate level. You might look at what insured people expect to see
in their plans and so forth. But pretty soon you come to the notion that you’re not
going to be able to afford adequate care for all just through cost savings by getting
rid of the unnecessary stuff. So you’ll run up to a point where you run out of
money. If there’s anybody in the bioethics world, as it were, who isn’t so much in
the bioethics world but is a senior fellow of our Center here, is Bill Schwartz,
who’s just come out with his book on Life Without Disease, basically arguing
why, up until now, we’ve had this failure of health care, and the eventual failure
of managed care to be able to deal with the constant increases in intensity of care
and the use of resources. And then his vision forward, and this is where Bill and I
part ways, is that eventually the molecular solutions, which are truly curative and
preventative, will be the kind of care where you finally see technology leading to a
decrease in unit cost of output. My sense is, all our experience has been in the
other direction. And I have a sense that the molecular is going to turn out the
same way, but that’s a separate issue. Pre-dating his work here, there was his
work on *The Painful Prescription* with Henry Aaron. So here is a person at our
Center, on the faculty here, who continues to look very explicitly at access issues.
And of course, at the time Clinton was putting together the health care ethics
group. I was asked to join that group, but I said my institution isn’t in a position
to fly me back and forth to Washington. I also said, “Moreover though, I think
this sounds like window dressing because it’s one thing to bring the ethics people
in at the very beginning and say, ‘develop the ethical framework and then figure
out practically what this means,’ or to bring them in at the end and really let them
critique what you’ve done and reformulate it.” But what they were talking about
is exactly what they did, which was to have all the technical and the ethical stuff
going on at the same time with minimal communication back and forth because it
was such a huge operation. And then having the ethics thing laid on the front end,
as it were, as kind of the fancy packaging.

SWAZEY: The window dressing.

CAPRON: The window dressing. That’s exactly what I thought, this will be window
dressing, I have no intention of being involved. Never made a wiser decision in
my life!

SWAZEY: You know I still laugh over Art Caplan’s story about how they knew they were
finished...dismissed. It was when they all tried to get into their parking lot and
discovered that their little cards no longer worked. They all said, “Well, I guess we’re done. We can go home now.” No farewell ceremony in the Rose Garden.

CAPRON: That’s right.

SWAZEY: Do you think bioethics, whatever that entity is, will gradually turn more towards these national issues?

CAPRON: I think so. In the National Bioethics Advisory Commission, we have from the beginning been talking about how can we revisit the Belmont principles and ask questions about values that were in some ways left out, particularly the values of community. I’ve argued informally, or through the e-mail, that we have to be careful how we do that because the community values were not absent from previous examinations. If you look at human subjects research, those values are in the premise that the community or the collectivity has an interest in the “advancement of science,” and that the only way to do that in medical science is eventually to use human beings. So a lot of what bioethics was doing then was calling attention to the risks that research poses for individuals when that collective interest outweighs the individual and you get the exploitation of subjects and their direct harm for the “good of the community.”

But when it comes to the health care side as opposed to the research side, I think it is true that the emphasis on informed consent and on personal autonomy never got much beyond the autonomy of the other persons involved. That is to
say, physician’s autonomy, which is the origin of the futility debate: should physicians not have to treat patients even though the family of the patient wants treatment? In health care, there has not been much of a framework for dealing with the collective interest. Because if you start off with the premise that the obligation, the bedrock ethic of the medical profession, is fidelity to the interests of the patient, then any explicit and even any strong implicit deference to or attention to the interest of others is the very thing the physician is abjured to avoid. And the physician promises in the Hippocratic oath always to put others, himself, and his community, behind the interest of the patient. So you have kind of an inherent tension in spending much time on community values. But we are going to try to talk. I’m not, between the two of us, a great fan of Etzioni, and the communitarian movement is pretty much his franchise. To the extend that there’s been a group that has been arguing community, community, community is important, it has been the communitarians and Etzioni. So that particular bandwagon is not one that I want to jump on. But if you think of the polity or the community in terms that you would use with your family, you would never blindly say, “Well, we’re just going to spend all the resources on one particular family need or one particular family member.” You would make judgments, and it’s inevitable and appropriate to make those judgements even in this area. We just can’t make them in the highly ad hoc fashion that is full of chances of prejudice
and discrimination against any one person. However, the notion that we're going
to say that certain treatments are, in certain circumstances, not ones which the
community can insure people get because that just isn’t as good a use of resources
that have to go to many other uses, including non-health care uses, makes
perfectly good sense and has an ethically defensible basis. The Access report
recognizes that it does not talk about everyone having access to anything they
want. We talk about the incoherence, indeed, of either a desire-or a needs-based
ethic.

SWAZEY: I have a feeling that you could republish the Access report, put 1998 on it, slap in
updated statistics, and people would say, “Wow!”.

CAPRON: Right, that’s probably true. That exactly what happened with our report on
Genetic Counseling and Screening because we used cystic fibrosis, which we
recognized as a future case. And four or five years ago, when the screening
finally came through, suddenly everyone was saying, “My God! We could be
screening every white person (basically because it’s not as big an issue in the
black population) in the United States. What’s going to happen?” Then a few
people who had read the report and used it in the genetics community said, “What
do you mean what happens? It’s right here in this report, they talked about all that
already and anticipated all these issues.”

SWAZEY: I want to come back to the various commissions, but let me ask you about the role
of bioethicists as public intellectuals. You are one of the people that Renée and I
would consider to fill that role in terms of....

CAPRON: The public side, if not the intellectual side. (Laughter)

SWAZEY: Depending on the day and your fatigue level! But you certainly are quoted in the
media, you’re up front and so forth. Do you see that as one of your professional
responsibilities?

CAPRON: Yes. That is to say, it’s a burden to respond to a lot of press inquiries, which I do,
and I know that it’s one that is going to lead very often to either a short quote or a
short sound bite that will be highly selected out of all the wisdom that I speak
forth. Or that may, particularly with reporters who start off on subjects where
they don’t know a darn thing and where you have to give them the half hour
course and sort of lay out in almost in outline form to them what the issues are
and who to talk to about them, end up on the cutting room floor. That is to say,
you provide all the structure and their article sounds as though it’s just what you
said to them but it’s not even something where they end up acknowledging that. I
realize that’s a way of starting out that sounds sort of sour grapesy. But yes, I do
feel that public understanding of the issues is important. I guess I’m with Thomas
Jefferson on my views of democracy; an informed electorate is the best thing. It
was actually one of the big disappointments of the first-year plus of the National
Bioethics Advisory Commission. For whatever reasons, some of which are
probably better left off the record, the Commission adopted a hunkering down view that was minimally compliant with the Federal Advisory Committee Act but doing nothing by way of real outreach. One of the things that I was very loud about was our failure to do the right thing there. One of the very best things that Eric has done is to bring Andy Burness in as a consultant on contract to help us to do a better job. It was one of the things that I think the President's Commission was very attentive to and reasonably good at, and I regard as an individual that it is important to do. The misunderstandings and the misquotations and getting the thing wrong is just par for the course.

A few years ago I was on a task force of the Twentieth Century Fund which was supposedly organized around the communication of scientific and technical risk to the public. I remember at one session we had in some scientists and heard from them their complaints, and why they or their colleagues had given up responding to press inquiries because the press didn't understand what they said. Then we heard from the press about how the scientists talk in gibberish and they couldn't get them to address what they thought were the real issues and so forth. And along the way one of the scientists said, "You know, when I look at The New York Times or The Wall Street Journal and I see the sophistication and the depth of coverage they bring to business, I just wish they could do it for science." Two or three of the people who were on this task force were big Wall
Street corporate businessmen, and they both laughed and threw up their hands and said, "The press does a terrible job on business! They get it all wrong, the stories are always confused!" So whatever field you’re in...the same complaint. And yet overall, the cumulative value of having these things discussed and analyzed is important.

My biggest disappointment with the press, and where I do feel frustration, is when they take the easy way out and call the small handful of people, and don’t seem to be particularly eager to follow up on leads to people who are more expert.

I suppose a lot of this in bioethics circles involves jokes about Art Caplan. Because of the slightly soft nature of what we do, it often fulfills the reporter’s desire just to have a short quote, to have one say, "This is a terribly interesting and important issue and we really need to think about it more." When I hear that on NPR or while I’m reading the paper, I want to scream and say, "People have thought about that! And there really is a literature on this!" There are people to talk to. You don’t just have to have the perfunctory, "this is a horrible development and it ought to be thought about."

SWAZEY: So contrast the way you see yourself playing the public intellectual with the role of Art Caplan.

CAPRON: Well, I don’t think the role is that different and I’m sure unbeknownst to me there are times when Art would be called and would make exactly that reference and
say, “Don’t quote me, call so and so.” Art is, I suppose in part because of the relationship with Gina Kolata and sort of being her main source on every subject under the sun, very widely quoted. But beyond that Art is very quotable. He has a good instinct for how to put things. I think most of the kidding about it is good humored.

SWAZEY: It’s good humored but I think there is also a sense in academic bioethics that Art is not a “real” scholar despite his PhD in philosophy because he does go to the public so much.

CAPRON: I think that’s probably true. I’ve heard people say there is no Art Caplan theory of whatever. But I’m trying to think of...I’m sure that people in the foreign affairs community listening to Henry Kissinger being quoted on something will say what I just said is often said. “There are so many people who know more about Croatia than Henry Kissinger. Why are you quoting Henry Kissinger?” Well, it’s in part that once someone gets recognized, and there is no Secretary of Bioethics, so he’s never been secretary of Bioethics, he’s quoted a lot. Art in fact has never been on any of these public commissions, but there is a recognition that this is a person who one listens to and he always has interesting things to say. And the same is, I’m sure, true of Kissinger; he’s on there because he is a former presidential advisor and Secretary of State and he’ll have interesting things to say even if he’s not the world’s greatest expert on whatever crisis he’s being interviewed on. So if
the choice were between the media not having those quotes and not at least
attending to this set of issues, and having it from someone who they can rely on to
return their phone calls and give them a good quote, I’ll choose the latter. I think
Art plays a role there. But if one searched The New York Times, The Los
Angeles Times, Chicago Tribune and so forth, I’m sure you would see a lot of
quotes from Will Gaylin, Ruth Macklin, Dan Callahan, and so on.

SWAZEY: Probably depending on the subject.
CAPRON: On the subject, right.
SWAZEY: Certainly recently with cloning it was Tom Murray who was on every channel you
put on or station you listened to.
CAPRON: That I think mostly was just because at a crucial juncture in the work of our
Commission, Tom was the person who was designated to go and testify. And he
then became the person who they called. He hadn’t done pre-existing work in the
field but it was perfectly appropriate that that happened. So there are a lot of
people who play this role. I wouldn’t contrast any of our roles with any of the
others. I think we all probably do pretty much the same thing, which is to try to fit
it into our schedules. When I went upstairs I had an e-mail from a reporter telling
me she wanted to send me a report to comment on - an AMA report from its
Council on Ethical and Judicial Affairs on this practice of physicians selling
products in their offices. I’ll have one or two calls a day like that from somebody.
I'm trying to think of something more comparable...maybe the whole idea of the public intellectual itself is kind of far-fetched. There certainly have been people, at various times; I suppose Bertrand Russell was probably quoted on all sorts of interesting topics simply because he was Bertrand Russell and he was an intellectual. The kinds of commentary on issues that ought to concern the public because they are developments, twists and turns on genetics, and death, and reproduction, and access to health care, and so forth. I guess it's the notion that I'm commenting as a public intellectual, as opposed to as a person who has some background on the particular field but I'm really trying to connect it with everybody's thinking. I'm not trying to connect it to a big intellectual tradition. I don't quote Kant and Hegel or even Thomas Jefferson to most of the reporters.

SWAZEY: I don't think I was using it in a Bertrand Russell sense, but more the expert who has thought and worked a lot on these issues being willing to take the time to engage with the public and believing that public education is part of their role responsibility.

CAPRON: I wasn't trying to argue with the category. I was just provoked actually to think, as you said, and began thinking in exactly those terms. Well, what will I do by way of contact with the media? But the whole question of what is that role is itself an interesting question. Does the notion of being a public intellectual mean being an academic who's willing to talk about some issue that he's analyzed to the
public or through the media to the public. It actually is provocative; what is this role?

SWAZEY: Let me get some more of your perspectives on the different roles that the three commissions have played, leaving out the Ethics Advisory Board. You’ve talked some about the differences between the President’s Commission and the National Commission.

CAPRON: I, of course, always want to bring in the fourth commission, the Biomedical Ethics Advisory Committee because I think there are lessons to be learned from the fact it never got off the ground, and because it helps to explain the present commission. The difficulty that the President’s Commission had at the end of its life ought to have been enough to indicate that the solution that Congress came up with was not going to work. That difficulty was that the Democrats in the House were worried that the people who were being appointed, who were then eight of the eleven on the President’s Commission, were not in the statutory categories that they were supposed to be in so that they didn’t represent the right mix of disciplines and expertise, and more importantly were too conservative and were going to be increasingly ideological. The miracle was how unideological the Reagan appointees were, at least as they were as commissioners under Morris’ leadership. On the other side, as though we were talking about eight totally different people, was the concern of the conservatives in the Senate, who then
controlled the Senate, that the people being appointed were not sufficiently
ideological, and were instead simply Reagan appointees because they had been
Reagan supporters who indicated this was the commission they wanted to be on or
something, and didn’t bring the true faith to the deliberations. So both distrusted
the continuation of the President’s Commission, which was why what had been
the plan to have a two-year extension just by changing the date of sunset clause
and not have it end in December of 1982, became instead a three-month
extension. The other thing that happened, just by way of historical footnote, was
that the original extension, the two-year extension, had been a little one-line bill,
literally, just that date will change. And Orrin Hatch had broken his ankle or
something and couldn’t get around the Senate very much. So he was sitting on
the Senate floor and was trapped, the story goes, by Barry Goldwater, cornered by
him, who extracted from him an agreement that he would allow Goldwater to put
in an amendment to create a National Institute of Arthritis, which had been a long
time interest of Goldwater’s in part because, I suppose, of his constituency in
Arizona. There had been constant disagreement from NIH because they did not
want a National Institute of Arthritis, and Hatch, as the chairman of the Health
and Human Services Committee or Health and Labor, had gone along with that
and said, “No, we won’t impose that on NIH.” But Goldwater got this promise
and so attached the Arthritis Institute to the extension of the President’s
Commission. So you had this little, tiny dog with this giant tail. And once the tail was there, you couldn’t pass the bill because there was so much opposition, not on ideological grounds but that just it didn’t make sense to create this Institute. So that doomed it in the fall of 1982. Then the extension was just favored by Kennedy, and I suppose Hatch became sympathetic to the notion that we had expected we were going to have an extension so they gave us the three month extension. Congress came back after the fall 1982 congressional elections and had a rump session in December. I think that’s when it was passed. What it meant was, we didn’t have to close down that month and we were able to do a much more orderly and nice completion on some of the reports. And as my staff pointed out to me then, I said, “All right, we have time. We’ll write another report.” That’s when we wrote the Summing Up report because I thought it was going to be worthwhile having in one volume the summary and tying together of our separate reports.

SWAZEY: Yes, that’s been very nice to have. I’m glad you pushed for that.

CAPRON: So that was all done in that last three months on top of finishing “Deciding to Forego Life Sustaining Treatment” and a couple of the others. The reason it really was a three-month extension, and not something more, was that there was this distrust from both the left and the right about what was happening. The solution that came out several years later, when Gore was still in the House and had
become the person most interested in bioethics after Ted Kennedy, was his notion, that there should be something that would have OTA as its model.

OTA mostly did a good job with these kinds of issues of evaluating things. So the thought was: maybe we can do bioethics the same way. I think what should’ve indicated right from the beginning that wasn’t going to work was that the major locus of non-agreement was in Congress itself, and it was set up with a Congressional Board in charge. The next indication of serious problems was that it took them two years between the time the statute was passed and the time we held our first meeting, during which time they managed to appoint the 14 of us who were the members of the Biomedical Ethics Advisory Committee. But it took so long that one of us had died by the time we met -- Dennis Horan (a right-to-life lawyer from Chicago) was dead by the time we had our first meeting! That became the stumbling block because some kind of process had been worked out where it wasn’t as though each member of the Biomedical Ethics Board from the House and the Senate could appoint one person, but they had some arrangement where they could each get one person on, and they had some kind of way of getting agreement on what the total composition could be. Apparently Senator Nicols, and I don’t know who else on the Republican side, ended up convinced that Gore’s staff had lied to them about who would be put up in place of Dennis Horan. They were even raising the name of Faith Wadlington, the head of
Planned Parenthood. Horan had been the head of Americans United for Life and they were talking about the head of Planned Parenthood as a replacement! So there was a sense of distrust and that apparently extended over to Gore, who had gone to the Senate by that point. There was a huge disagreement between the Republicans and Democrats over which Senator would chair the Board, and who from the House would be vice chair. Partisanship was running out of control.

There was of course, running through this whole thing, the concern about the right to life issues. I honestly believe, and there’s no way to test this, that we on the Advisory Committee at our first meeting had framed our own issues, particularly around genetics. At our second meeting, which I organized with Bob Cook-Deegan, who I had hired to be the acting executive director since we were still waiting for all the budgets and everything to be confirmed, we agreed to focus on the cutting edge, molecular medicine things, and just keep ourselves away from abortion. Because I had the sense, from my experience on the President’s Commission, that if you can get people working together for a while on issues where their particular proclivities and predispositions don’t come up, they will surprise you on the positions they take on these other issues. They will react more thoughtfully and over time will get experience working with each other, and when those other issues inevitably do surface, they’ll be less likely to look at the person across the table and say, “You’re here on the other side and I just won’t listen to
anything you say.” By then they’re used to that process and they think, “Alright, I
may disagree but let’s hear...well, that’s an argument.” The very same thing that
we try to cultivate with our medical students of being willing to credit that
somebody might have something to say even if you think you are going to
disagree where they’re going to come out. Of course, after our second meeting
was when the stuff came to a head with the senators and we were told basically,
“You can’t meet again until we work this out.” Then just to make sure it was
clear, I went in for our appropriation and testified....

SWAZEY: You were chairing....

I was chosen as the chair of the Commission and Pellegrino was the vice chair. I
don’t remember if the hearing was on the House or the Senate side; I think it came
on the House side. They amended the bill to say that none of the funds
appropriated could be spend until the fourteenth member of the Commission had
been named, and the chairman of the Congressional Board had been named.

Well, they couldn’t agree on either of those things so then, in effect, at the end of
that fiscal year we had to shut down actual operations and we were never allowed
to meet again. So we held one meeting a few days before our authorizing statute
expired. Then they extended the statute. They gave us the appropriation for that
year but on the condition that we couldn’t meet until this was worked out. And
these very grown-up people who are senators and representatives, our leaders,
couldn’t sit down and get to the point of choosing one of them to be chair and
naming someone to replace Dennis Horan. So with our statute still in place, we
folded our tents and expired.

SWAZEY: As you said, there are lessons to be learned.

CAPRON: Yes, and one of those obviously came up in the subsequent years when finally
there was some renewed interest, particularly by Mark Hatfield on the Republican
side, and Kennedy still on the Democratic side. Hearings were held around what
to do about all this. OTA was commissioned to do a report to examine the past
history of the different commissions and so forth. Hatfield wanted to create
something like the President’s Commission with an authorizing statute from
Congress but with appointments by the President. He just couldn’t get that
through. I don’t know why; the people on the Hill will have to tell you the history
of that. But with Ruth Faden’s Radiation Commission coming to such a strong
conclusion that there were major problems that still needed to be addressed that
grew beyond the radiation experiments, and with the interests of people like
Hatfield at having the genetics issues looked at, the solution was to come up with
something that doesn’t have the statutory base but instead operates from an
executive order. I don’t know if it was inherent in that format or if it’s a reflection
of the personal views of the relevant people in OSTP or the White House, but one
result of it not having that Congressional basis was that the format chosen by the
White House and OSTP in chartering NBAC was to have it operate as a
subcommittee of the Science and Technology Council, and to lodge it much more
firmly in the Executive Branch than had been true of the National Commission.

Starting off on the President’s Commission we were looking at the National
Commission and thinking where its strengths and weaknesses were. There was
the complaint of people like George Annas about the National Commission, that it
had been too much dominated by medicine both in its membership and in being
based at NIH. I thought, thinking about the President’s Commission, I can’t do
much about the membership because the charter says basically who you should
have, and the original appointees were pretty much according to the charter. It
wasn’t as dominated by medicine; there was a slight preponderance of non-
physicians on it. But I can do something about making sure it’s as independent of
any of the government agencies as possible. I think that was a great strength of
the President’s Commission: we were not lodged in a government office, we hired
our own staff, and we had our own appropriation. The first fall, as I said, Morris
was getting money reassigned and that’s when Pat Harris did in the Ethics
Advisory Board, in part to get the money and in part because she didn’t
understand that you can have both an Army and a Navy, basically. But the
National Bioethics Advisory Commission doesn’t have that; it was originally
staffed and supported out of the Office for Protection from Research Risks,
though it’s very obvious to anyone looking at our mandate that questions about
how well that office is operating are a big part of what we are doing.

SWAZEY: It’s the same problem we had on the Commission on Research Integrity. They
were staffing us.

CAPRON: Right. So what are you going to do? Our first acting director was Bill Dommel,
who was an assistant director under Gary Ellis. The second thing is that we don’t
have that independence, we don’t have our own line item appropriation, we don’t
go before Congress, we don’t have those linkages.

SWAZEY: Are you still staffed by OPRR?

CAPRON: Not exactly, no. I’ve never actually been to our offices, frankly; we never have
anything at the offices.

SWAZEY: They’re not bad...a little crowded.

CAPRON: They should be more crowded. I think initially it was very frustrating for Harold
Shapiro, about six months into it when it wasn’t at all clear where the
appropriation for the next year was coming from, and what staffing was going to
happen and so forth. He said to me, as he said to others, “If they don’t do
something soon I’m going to make it clear to the President what the consequences
are and I am going to resign. I won’t put up with this!” They did come through
with more of the staff slots and more of a guarantee of the money. Once we got
the cloning report done, and from the President’s view did so nicely on that report,
there was a statement that “I’m extending you.” And the Commission’s life was extended, which took away the uncertainty that we’d be ending as of October last year, and assurance that the funding would be there. So that in a way, the brief history and early demise of the Biomedical Ethics Advisory Committee, BEAC, is historically relevant. It is not just a contrast with the President’s Commission. Part of the reason we got to that was that the Congressional side of things seemed to be so incredibly screwed up. So I think it made sense to the White House to say this has to be something which is run on an executive order. I think they overreacted and there was a real sense that we were going to be babysat, as it were, by OSTP and there were really very heavy requirements that looked as though this was designed to prevent a runaway Commission of some sort. The agenda always has to be approved by a federal officer, which basically means one of the assistant directors of OSTP, Rachel Levinson. And for the longest time after Dommel left, our nominal acting director was Bill Raub, who had very little interest in any of this.

SWAZEY: Has OSTP, other than the formalistic requirements, pretty much left you alone?

CAPRON: I don’t know what went on behind the scenes with some of the cloning report stuff. Harold Varmus was not entirely delighted with some of the directions we were going in, I think that accounts for how we backed off a little bit on the research side. I don’t know the extent to which OSTP’s views.... This may have
been the perception that commissioners had on the previous commission, on the
President’s Commission, but I certainly felt as a commissioner during NBAC’s
first year, that I wasn’t in on most of the decisions that Harold Shapiro may have
been making with people in the White House or OSTP about how things were
going to be shaping up.

SWAZEY: Let me ask you one final question for today. Should there be a national standing
bioethics committee, the type of thing that Jay Katz has advocated for so many
years?

CAPRON: Well, I’ve advocated it too in print. So yes, I can give you a short answer to that.
I can give you the articles in which I’ve said that.

SWAZEY: Where should it be based? And how should it be organizationally structured?

CAPRON: This is perhaps nostalgia, but I think that the arrangements that characterize the
President’s Commission were more or less ideal. As I said before, when one is
talking about the subject of informed consent what I learned from Jay was all the
things that are subterranean, that really affect what a doctrine like that means in
reality. So too, the formal structure of the President’s Commission may not
explain a lot of the reasons for its success that I ascribe to some of that formal
structure. It may be the serendipity of who the commissioners were, who the staff
was, what the chairman was able to accomplish because of his rather unusual,
unexpected, and unique relationship with two successive White Houses, as well as
his personal skills as a persuasive advocate. But I do think that the structural
characteristics were ones which were conducive to having the ability to dig into
issues without too much concern about political or bureaucratic ramifications.
One of the advantages of having a standing body is that you don’t have
commissioners appointed solely because somebody who’s doing the appointing
makes a calculation as to how many votes this means on one view or another of
the issue that’s being looked at. I think one of the reasons that the commissions
that looked at the use of fetal tissues, a couple that NIH convened in the period
when we didn’t have any other national body, ended up being more or less
footnotes to history and not influential in what happened, was precisely because
everyone who was appointed on them was appointed with a view as to where they
would probably come out. They were regarded by the people who really had the
decision, more or less as holding operations because they were not free inquiries.
If you have a group that’s looking across a range of issues which are added to over
time on their own initiative or on the request of others, you have a chance for
fresh examination of a topic because people’s past positions on unrelated issues
are not indications of where they are going to come out. You also have
something, not to be grandiose about it, akin to what the Supreme Court does.
The Supreme Court doesn’t have troops and brigades of policemen, they have a
small number of marshals. That’s not why their judgements get executed and
respected, despite public roiling over school desegregation and abortion and a few other topics through the years. Generally, when the Supreme Court pronounces on something people take it as having great weight, and it’s because the institution has some credibility. I think that a standing commission has the possibility of having that kind of credibility. The big disadvantage of having a standing commission is on the staff side; you have to be clear to people that there are objectives of getting things done and moving on to new topics even though you don’t have an absolute deadline. Those deadlines were very useful for me in getting incredible work products out of the people who were working for the commission.

SWAZEY: A standing commission doesn’t preclude deadlines, does it?

CAPRON: No, it doesn’t preclude deadlines but there’s nothing like the prospect of termination, not out of spite but just because that’s when the statute expires. Like the prospect of hanging, it does focus one’s attention.

SWAZEY: Let’s go back to the discussion yesterday about the commissions and human experimentation, and get your sense as to why it has been a recurrent focus of all the commissions including NBAC. What is it about research with human subjects that makes it constantly a major policy matter for the commissions?

CAPRON: I think there are three reasons. The first is that so much of the research has been
sponsored by the government. And so when you have a public commission it is a
natural topic. When you look, for example, at decisions at the end of life, which
is a topic that the President's Commission took up on our own initiative, that's not
one that inherently involves the federal government at all. Obviously there are
issues of state law and many issues of hospital policy and ethical guidance coming
out of religious traditions and so forth, but that wasn't in our mandate. I don't
think it was absent from our mandate because it wasn't federal. The
determination of death issue is not primarily federal either. But the major role the
government plays in sponsoring research with human subjects is the first reason.
The second is that regrettably there have been over the years so many instances, I
was tempted to say scandals, of abuse of subjects. Each generation seems to
uncover a new batch of them. They're not always new. The Tuskegee study,
which prompted the National Commission's establishment, was something that
had been going on for 40 years. The Radiation Panel, which certainly lies behind
the present commission's having the experimentation issue as a mandate, was
looking at research that also went back 30 or 40 years. So it's not as though that
each generation has its share of bad research projects, it's just that each generation
finds the issue in very real terms with death and suffering and injury. And I think
the third reason is that the subject itself is in some ways one of the most difficult
and constantly debated subjects. It isn't driven by technology. You could say that
we didn’t have to worry about cloning until the technology was here, though you
could have speculation and science fiction and so forth. But the question of
human experimentation goes back to the dawn of medicine. The tension that’s
embodied between people who would say that the advancement of science and
knowledge is an overriding good, that all of us alive today benefit in uncountable
ways from the advances that came before, that the vaccines and treatments and
just knowledge of physiology and metabolism and everything else that we have
today, came about because others have been human subjects in the past and that
creates some sense of an obligation. That obviously becomes most relevant when
one is looking at children and the mentally retarded, people who can’t make those
choices themselves, and asking, “Is it reasonable to ask of them some sacrifice?”

At the other pole, the view, I suppose, is best articulated by Hans Jonas back in
that *Daedalus* volume: that there is a hierarchy of values, and that the human
values around the protection of the human being and the integrity of that human
being are of much greater importance than progress. That scientific progress is an
optional goal, it’s not a mandatory one, and if it is bought at the cost of the
sacrifice of any of those core human values, including the respect for the integrity
of the individual and the choices of the individual, it’s not worth that candle. That
can be expressed in any number of different ways, but that tension between the
two different views and all points in between, means that it’s not as though one
can simply say, in response to the scandals and to the reality of the government
sponsorship, “Here’s an easy solution to that: just behave ethically.” To me that
was always the difficulty of Harry Beecher’s solution. Having catalogued all the
problematic articles from *The New England Journal* for one year he then
concludes that the best protection is the conscientious physician. I don’t know
what a conscientious physician would say when faced with some of these
dilemmas. There are ways of arguing any position there that makes sense. The
core tension, as we said in the *Human Experimentation* book right at the
beginning of the introduction is, when is it permissible for one person to sacrifice,
to place at risk another life or well-being for the good of society or for the good of
others? That’s a question that is age-old. There are many other manifestations of
it. The choice to mobilize an army to defend a country has that tension. The
choice to make certain uses of land, to make allocations of resources, even
deciding to spend money on cops and streets instead of schools and libraries or
something; you’re sacrificing something else with each choice. But the effect of
those is usually indirect and hard to see in the long term. A group doesn’t do as
well, or prosper as well, or is faced with burdens or something like that. Here it
can be injury, mutilation, death; it rarely is in research but when it is, when it’s
something like the radiation studies or something like Tuskegee, it reminds us that
the potential is there, in all research.
I may be overstating it, but have you seen a paradigm shift over the last couple of decades from protecting rights and welfare to insuring the right to participate in research?

Access.... Yes, and I think that there is no question that paradigm shift occurred. I think most people, probably historically correctly, identified that with AIDS. When you have a disease that is taking so many lives of people who would otherwise expect to be healthy, any chance to stem the fatal illness is seized upon. Just within the last day or so, The Wall Street Journal had an article talking about the fact that drug companies running trials on drugs that had gotten through all the processes and are now in phase 3 testing, are not infrequently faced with the problem that the drug either doesn’t really work or that it actually is harmful. The best companies build in an assessment mechanism that allows a stopping rule for the research. This was in contrast to one of the small British biotech companies that got into trouble with a drug and the head of research was breaking the blind, not in an orderly way with a review process, and how that then raised these questions. The article went on to say that the experience of drug companies is that 9 out of 10 of the drugs that get very far along, which they’ve invested hundreds of millions of dollars in, fail. Now that ought to be a reminder to the public that the old paradigm, the protection paradigm, actually makes a lot more sense, not just with AIDS, but with breast cancer, with any illness where the prospect of not
getting the best treatment is very worrisome because present treatments are inadequate and the illness is extremely crippling or disabling or fatal. The desire to get into research now has certainly shifted that paradigm.

SWAZEY: So what do you do with the paradigm shift?

CAPRON: I, myself, am very skeptical of it, as my mention of this information from the pharmaceutical world indicates. I'm very concerned that people end up exposing themselves under a false assumption about the ethicality of what's going on. That is only part of this broader problem of the therapeutic misconception that exists in such a large number of subjects.

Let me just give you an example that we came across, which I think is going to affect what we do with this report that we're working on now at the National Bioethics Advisory Commission. One of the topics we're looking at is research with subjects who are mentally disabled in some way. Specifically those who have kinds of mental illnesses that would impair their ability to consent.

Those who are at the greatest risk are obviously those who are institutionalized, but it's not only those who are institutionalized with schizophrenia or other psychosis. Perhaps some of those who are most at risk are those who are on an out-patient basis. In looking at this last fall, we had a hearing for a couple of days and we heard from a lot of families and some people with mental illnesses who had been research subjects, and we talked about the problems. Then we heard
from one of the leading researchers in the field, a woman named Carol Taminga
who’s from the University of Maryland. She was an extremely reasonable and
thoughtful person. We asked her a lot of questions about consent and she said all
the right things about how they try to make it a process. They don’t just use the
documents. She knew all the right things to say and seemed intelligent and very
genuine. Subsequently, I got a research protocol for one of her studies that had
actually been published. The research was done in the early 1990’s, and the
publication came in the mid-1990’s. This was one of those studies using ketamine
as a challenge for people with psychosis. As I read it through I was simply
staggered because it referred to it as “a treatment for your illness; a new drug” and
so forth. And it wasn’t! If you read the protocol and read the results from the
study, they were doing a challenge to see what happened to blood levels and so
forth.

SWAZEY: It was non-therapeutic research, the term that Bob Levine can’t stand, but I still
think is a very useful term.

CAPRON It’s a very descriptive term. This is research with no intent to do benefit. I think
Bob doesn’t mind non-therapeutic research, what he minds is the opposite: the use
of the phrase “therapeutic research” because that just underlines this therapeutic
misconception. Of course, I wrote her a letter going through the thing line by line
saying, “Can you explain this?” I kept thinking, I must misunderstand some of
this, this cannot be that bold. I’ve never heard back from her; I heard from her lawyer but I’ve never heard from her. And so what I got the Commission to do was, I said, “Let’s have the staff look at five years worth of publications in the literature of studies that involve subjects who are probably, by the description of the study, at risk of impaired capacity and where the study would involve more than minimal risk.” Then after we identify a bunch of those, which has now been done, let’s get the protocols and the consent forms and look at them and see how widespread a problem this is. We can then say such and such percentage, because it is not a controlled or complete study but we get a sense. We don’t know the answer to that but I will not be surprised if Tominga’s study was not unusual, anymore than the UCLA challenge and the washout studies and so forth turn out not to be unusual. Jay Katz, of course, has written about the consent form that was used at UCLA and pointed out that it seemed to place a great deal of emphasis on warning people about the risk of the blood draw that was going to be made to measure the level of blood, which is an absolutely minor risk. There was nothing to alert them to the risk of going off their anti-psychosis medication. As I thought about this, it seemed to me that the problem is it’s just darn hard to sit down across the table from someone and tell them bold, right out, “I don’t want to do you any good at all. I want you to do some good for me and I’m going to put you at more than a negligible risk in the process. I believe we’ll be able to
intervene if anything goes wrong and bring you back and so forth. I don’t think
this is going to do you any permanent damage but it’s not for your benefit.” It’s
just darn hard to think how a person has that conversation. Now it may be, as we
know in the history of research, in the modern history, that there are people who,
when confronted with that would say, “Well, I’ll do that. I know I’ve got a
disease that is incurable for the moment but if, ten years from now I can think of
someone else who has that disease....” There are people who respond to that guilt.

SWAZEY: They are altruists, but when they’re mentally disabled with impaired consent....
CAPRON: This was just a window into the problem.

SWAZEY: It’s hard enough with somebody who is “normal”.

CAPRON: Yes, right, but it’s not unique there. I think one of the reasons that therapeutic
misconception exists is that it is fostered by the researchers. And one of the
reasons they foster it is not solely to gather in subjects, but because it’s hard to do
that just as a human interaction. Then of course, you get into the subsidiary
questions: if you are going to something like that, should it be with people who
are not your own patients? Isn’t it much better to have a researcher coming in as a
stranger and say, “I’m from research, this is what science is all about, this is what
we need to do if you’re willing to participate. I would like to enroll you but you
don’t have to, and I’m not your doctor and you don’t owe me anything.” Rather
than the not atypical situation where someone is researching with his own patients
and that sense of, "Gee Doc, you've done so much for me....", in the spoken or
unspoken sense.

SWAZEY: Does the Belmont Report need updating at this point, twenty years later?

CAPRON: In light of this question of the shift of the paradigm, I think it needs to be looked
at again. And in light of some of those issues that were not as directly addressed
about the value to the community. I suppose there's the underlying question: Is
the Belmont Report solely about research? Or is it like Beauchamp and
Childress' book, which doesn't pretend to be about research? It is about the
principles of biomedical ethics that are broadly applicable to the full range of
questions, whether it's surrogate motherhood, or organ donation, or whatever.
Certainly in that context those principles, if they are going to be more widely
applied, deserve attention. The issues of balancing the individual and the
community may be as a sub-heading under justice or something. And then there
are some questions about context and reality, for example the risks of
discrimination, and exploitation and so forth, which you wouldn't know were
risks looking at Belmont. Obviously in telling people you have to have respect for
persons, that means you don't discriminate against them and you don't exploit
them, but it doesn't say it that way. It acts as though one is dealing with the
shadows on the wall of the cave, just abstract concepts. Not the gritty reality of
research going on at public county hospitals where people are not a cross section
of the population. A long list of things.

SWAZEY: I gather the IRB system is once again one of your mandates too?

CAPRON: Yes.

SWAZEY: I think it was Gary Ellis who said we don’t have a lot of control over IRBs, and by that he apparently meant because they’re dealing with such an increasing percentage of non-federally funded protocols. What’s your sense about this?

CAPRON: I think those are two separate things. Some of us have believed and argued for a long time that we shouldn’t have a system that makes it optional to have review of research that is not federally funded. The handle we have there, of course, is if it’s research that is in aid of a new drug application, you still have IRB oversight under the FDA’s regulations. You also have the fact that for a while in the 1980's, though I don’t know the extent to which Gary still does this, the federal government was substantially exceeding its statutory authority by, in effect, coercing IRBs and institutions to agree that they would voluntarily review all research that came before them. Now, if you play this tape for Charlie McCarthy he’ll deny that’s the case. I think, in candor, they made it clear to IRBs and to institutions that the best way to be regarded as a good actor, a good player, was to agree to do that. It was voluntary but that was sort of the standard form that was suggested that they ought to be signing on to. If institutions said they weren’t going to do that, the federal government doesn’t have, didn’t then and doesn’t
now, have authority to insist otherwise. The inability of the OPRR to have any
real control or oversight over the IRBs results from the fact that it is woefully
understaffed and has always taken a very deferential view. I think that deferential
view grew out of the history that the IRB system was laid on top of the external
grant-giving arrangement that had already been struck between NIH and the
institutions. At some deep political level, I suspect that the reason is that many of
those institutions were fairly powerful players in their local jurisdictions. And
that they made it clear to their members of Congress that it was fine for them to be
funneling a lot of money to this research institution at Bethesda, but certainly
some of that support that was being spent, millions and billions of dollars that
were being spent by the federal government, ought to be flowing into their district.
Specifically to the University of XYZ, which was an ornament of that district.
That, as I say, is a somewhat cynical view of the arrangement that the research
community had amongst itself. External grants were going to be this percentage,
and internal funding was going to be that percentage, and we can both grow and
we can support each other in that process; but don’t keep it all at Bethesda. There
also was the conception that the best research is going to be that where the
institution is, through its research scientists, developing the agenda and the R01
idea. That basically you do the best by letting people respond to a general area of
interest with their specific protocols rather than trying to micromanage out of
Bethesda. Even under the “war on cancer” there was still a huge pot of money that basically was available for anything you wanted to do. And for years and years the joke was, everything was “and cancer” on the grant. It would say, “hypertension... and cancer” on the grant, even though hypertension was the interest. So when the system for protection from research risks came along it was just laid over that, with the same idea, that basically the institution should be in charge, we should delegate this, what we want to do here is the same as we do in research, which is count on the institutions to do the right thing.

SWAZEY: Henry Beecher’s ethical investigator.

CAPRON: Exactly. I think driven not only by Beecher’s ethical orientation and professional orientation toward thinking that the individual is the right thing, but also a political push. Decentralization, that’s going to sit better. NIH was not at the time, and mostly today is not, even with the overlay of research ethics of the scandal type, a regulatory agency. That’s the thing about it: it’s not a regulatory agency so its mentality was not: “We’re going to regulate at some minimal level. You have to account for what you spend but we don’t expect to be regulators.”

Now when you’ve got human subjects and animal subjects there is some amount of oversight that’s necessary. Actually, of course, the argument for many years has been that our rules on animal oversight are stricter and require more reporting of how many you are using of what type and what you’re doing with them, than
we do with human subjects. I think historically that’s a big part of the
explanation. In the late 1960's and early 1970's, after The Surgeon General’s
establishment of rules for the NIH intramural work, you then get a number of
research institutions having a somewhat broadened research oversight thing.
Bernard Barber’s et al.’s study documented both that it existed and that it was far
from complete. Which is why, I think, when Congress decided to impose the IRB
system and the statute that created the National Commission, they were simply
falling into the familiar without really thinking -- “Is this really the right
regulatory system?” They just picked up on what was already there and said that
the real problem is the unevenness of it, that not every institution by far has such
research protection.

SWAZEY: What major ways would you strengthen the system if you could wave your magic
wand now?

CAPRON: Well, at a minimum I’ve always felt value in one of the recommendations that the
President’s Commission came up with, which is that we should have coordination
of the HHS and FDA approaches, and that there should be regular site visits to
every IRB by teams that were principally peer review teams. And that the best
way to strengthen them was to have someone come in who did not have the
bureaucratic mentality of the FDA inspector.

SWAZEY: The famous meat inspector.
CAPRON: Yes, exactly. I don’t know the extent to which the inspectors who now do it are
more specialized, but at the time it was the people who were looking for rat hairs
in the tuna fish who then would show up and be rifling through IRB files. Who
knows if they knew what they were looking for and what was a good IRB or not.
It sounded at though that was money being spent and probably being wasted.
Conversely, OPRR knew nothing! They had the initial negotiation which in many
cases was kind of pro forma. An institution gave an “assurance” and then only
when there was a problem of enough magnitude to really make it into the press, or
to generate a major complaint, did OPRR go out and find...usually they didn’t
even go out. Usually it was an exchange of correspondence; they didn’t have the
staff or whatever. One of the things the Commission said in one of our two
reports on the regulation of human subjects research was that what would make
much more sense was an evaluation of IRBs we pilot tested at a number of
institutions. That was intended not only to improve the performance by sort of
shining a spotlight on having people know that they were really going to get
looked at by people who knew something, but also to give IRBs the sense that we
can learn from each other. There is always a risk you’ll get someone on a site
visit, maybe a team, who will have a particular “bug” about something and may be
heavy handed. There is always some risk, and you hope that the other members of
the team will recognize that idiosyncracy with this person, and you don’t have to
adopt his view. But on the other hand... "Gee, at our institution we had the same
kind of issues that we have here and one of the things that we’ve done that worked
is this or that. I’ve been reading through your records and you seem repeatedly to
have this issue or that." Or "we talked to members of the Committee, particularly
the non-scientists, non-institutional members, and they don’t feel that this or that
is happening. They don’t understand and maybe this educational thing that we
have done...." Just using, in the best sense, a peer process. The same way that
researchers look at each other’s research projects and make suggestions for
improvement.

SWAZEY: Did the Commission have a chance to comment on the ORT grant before them?
CAPRON: No. Well, Eric Meslin gave testimony but the thrust of the testimony is, "we’re
working on some related projects." We’ve had papers from Charlie McCarthy
and John Fletcher allegedly intended to be different views. McCarthy was going
to be con and John was going to be pro on this issue of: Is OPRR institutionally
in an impossible position? My view is that it is. You cannot have someone who
is that far down in the NIH bureaucracy exercising control in any effective way
over research that’s sponsored by other coordinate groups like CDC and so forth.
You cannot have someone like Gary Ellis who has to go in and see the director to
defend his budget and his actions, who knows that the director is hearing from
institute directors, "We’re having a terrible time! Here’s this whole line of
research and these people are ready to go and OPRR is giving us problems about
it.” NIH itself didn’t comply with OPRR comments about its own IRB process at
the Clinical Center for a couple of years.

SWAZEY: They certainly have not been handling misconduct allegations very well either. I
certainly have a strong sense, as I wander around, that IRBs don’t take OPRR
seriously, or their institutional officials don’t. A lot of IRB members don’t even
know what OPRR is. So I think you’re right, they don’t have much clout.

CAPRON: And so the debate between Charlie and John turned out to be, not whether or not it
should be moved but whether, in Charlie’s view, it should be moved to the Office
of the Secretary. In John’s view, which I favor, it should be established as an
independent commission, just like the FTC and so forth, smaller than all of those
but still.... And that it would have a staff that would have responsibilities
government wide, as OPRR, in many ways, already does. It is the lead agency but
it would have clout which it couldn’t have if it was in the Secretary’s office.

Because if the Department of Transportation is sponsoring research with human
beings on transportation safety and some problem comes up about it, somebody
from the Office of the Secretary of Health and Human Services is going to be told
to “butt out” if they are too interventionist, but an independent agency wouldn’t
be. I think everybody agrees that’s the case; even Charlie would agree that there’s
more ability to be effective if you’re independent. Also, one of the things that
John developed, which I like very much, is the notion of an ongoing group of citizen commissioners. Probably not as large as the present Commission, more like eight to ten people or something like that, who would be in an oversight role to make sure that what goes on here has visibility which a purely bureaucratic office headed by permanent staff, can’t have. It makes the difference. It wouldn’t be like the Federal Trade Commission where you have a number of appointed people who come in and are working full-time. It would be like our commissions, but besides its hands-on involvement with the function of IRBs, if that’s even the right system. It may end up developing a non-IRB system, take it out of institutions. There are a lot of conflicts within the institutions themselves. It would look at issues like that, but beyond whatever it did on the actual day-to-day research projects, it would have a group that could look at these broader issues and give guidance as to what do we need, as we are now doing with special protections for subjects who are mentally impaired, and be able to carry on that process but keep everything at a higher level of visibility. You have someone like Harold Shapiro on a commission like that and you know that if there are problems being uncovered he has the ability to make those understandable to the general public in a way which Gary Ellis can’t. Just because of his employed bureaucratic role, even if he were the staff member for an independent body. About a year or so ago, Gary talked to someone from The New York Times who wrote a story,
about the fact that there is much more protection for animals than for human beings. His picture was in the paper and all that. I thought, “great story!” Well, of course he was told, “You don’t talk to the press anymore. No comment is your comment from now on.”

SWAZEY: Never mind reality!

CAPRON: Right, exactly.

SWAZEY: Of course animals have always had very vocal constituencies, human subjects haven’t. It’s interesting political dynamics.

CAPRON: So I think that if I were redesigning, which is what you asked me originally, I certainly would ask questions about the continued viability of IRBs. I would certainly insist that whatever mechanism we have should encompass all research whether it’s sponsored by a foundation or a private sponsor, or patient money, or drug companies, as well as by the federal government. There is no reason why people who are recruited should be treated differently. I very likely would want that oversight mechanism to be out of the sponsoring agency. The analogy I used in making the motion that we move in that direction was the Atomic Energy Commission. We learned our lesson. You cannot have one group be both the watchdog of safety and the principal sponsor, and that’s what NIH is right now.

SWAZEY: The fox guarding the henhouse. That’s always been a problem.

CAPRON: Right.
SWAZEY: It's sometimes hard to see it from the inside. Let's talk a little bit about what you see as some of the roles and relationships between bioethics and religion. It's been something that's interested us looking at the very influential people that started bioethics....

CAPRON: ...and their general absence today.

SWAZEY: Right. What's happened?

CAPRON: I think probably a lot of the answer lies on the religion side, as opposed to the bioethics side, and I can't really comment about that. I don't know all the dynamics within the religious community. I do know that I was participating, a couple of months ago, at a day-long forum that the University of San Francisco sponsored with the Archdiocese, on Catholic views on death and dying. The lead-off panelist was a dean of a seminary down in San Mateo, apparently one of the leading Catholic seminaries on the west coast. He talked about the religious Catholic views on death and dying. Another speaker was Carlos Gomez from the University of Virginia, who has written a lot about death and dying and studied the Dutch suicide situation, talked about being a Catholic doctor. Other panelists were Peggy Steinfels from Commonweal and Peter Steinfels from The New York Times, and then they had a person who is a political consultant who had advised on some of the opposition to the legalization efforts for assisted suicide and euthanasia but who also advises candidates. He was talking about the political
side. One of the things that Carlos had said in his very interesting talk, was that if he were speaking to his colleagues at the University of Virginia Medical College, giving a talk about the same range of issues about how to care for the dying and palliation and so forth, he would not be using the same language. He would not be using the same reference points and it wasn’t just that he, like a couple of the others, was talking about his own Catholic education. Everybody seems to have had a Jesuit who was so influential in his thinking about whatever it was, and then various nuns who scared the bejesus out of them. (Laughter) Those are the two hallmarks of a Catholic education, as far as I could tell. As I said, it was called “The Catholic View in the Secular World” and I said, “I’m here from the secular world. I was raised Unitarian.” The audience was primarily a general audience. There were certainly nurses and physicians there but this was not a medical conference. There was an overflow crowd. I would say it was an older crowd, probably some people who were there mostly because of their own concerns or whatever, but Catholic lay people basically.

One of my comments was that not only of a lot of physicians and nurses but also people from ethics and even religion today, talk in secular terms. Even though for themselves their understanding of these events as part of the world, and of life, and of the way they explain things to themselves, and experience things, are much richer than that. This drew wild affirmation from the audience. I didn’t
say it as an applause line, I was just reflecting on what I had heard. I really think people should speak in their authentic voices about what comes from their tradition and what their tradition has to teach. After all, the ironic thing is that a lot of modern American common law on these death and dying issues come right out of Catholic theology. It’s in part because of the Quinlan case where the family brought some of that in from what seems to have been a very well informed parish priest, who didn’t react a la the abortion debate -- we always protect life -- but reacted quite correctly reflecting....

SWAZEY: As a parish priest.

CAPRON: Also, but reflecting papal doctrine about the ordinary/extraordinary distinction and the fact that fighting off death is not the highest objective when it becomes a burden that is excessive, including a burden for the family. But in any case, as I say, I wasn’t just reflecting on Carlos’ comment but on the fact that outside of the abortion debate there isn’t as much attention, I think, to the spiritual in these discussions. Someone like Paul Ramsey obviously was analytical in what he was doing, but he spoke as a Christian, he spoke from a tradition. Joe Fletcher, who took the opposite side, was also drawing on a tradition, perhaps more Episcopalian than Ramsey’s. I guess Ramsey was a Baptist, at least I think so.

SWAZEY: And obviously Jim Gustafson was a giant figure.

CAPRON: Yes, and Jim was enormously influential in the first decade and then moved on to
other things. He may have decided the waters were too shallow here to be
interesting. But that kind of analysis at the academic level has been remarkably
absent, and it certainly has been very thin gruel on the public discussions. One of
the reasons for that is something which we saw on NBAC with the cloning
discussions. I said to Harold Shapiro, “I think we absolutely need to make sure
that we immediately hear from the religious communities about this.” For two
reasons: first, we may learn something. If you’re dealing with a totally new
subject, one way or another Americans are religious people. Some people talk
about the fact that we are church-goers but we’re not religious and so forth. But
people believe that religion would have something to say about this. Second, if
we don’t do it we will be attacked for having ignored it. The consequence was
that at the first hearing the Commission held on the subject, we in fact had
Muslim, and Jewish, and Catholic, and Protestant, representative testifying.

SWAZEY: ...which was a very striking event for those of us who tuned in.

CAPRON: Yes, it was. We recognized right from the beginning that there is a dilemma in
doing that because you can’t simply turn around and say, “The Commission
concludes that because the Bible says....” That’s clearly off the table with the first
amendment. You cannot base your recommendations for public policy on
religious doctrine.

SWAZEY: Is that one reason why the religious voice has...I guess I would almost say, hasn’t
vanished; it’s gone underground? Because once bioethics started going to
Washington it was translated into secular dialogue.

CAPRON: Yes, that was my purpose in talking about this. I realize that even as I talk I tend
to want to go to the example and build up from it, rather than announcing the
principle.

SWAZEY: That’s alright, that’s the legal case approach.

CAPRON: But I realize that it’s frustrating that I sometimes don’t identify what point I’m
making. Yes, that’s exactly the point: to the extent that bioethics is in the public
arena that way, you can’t have it be as grounded in religion. Paul Ramsey wasn’t
writing as someone writing government policy. I think once he got beyond The
Patient as Person, when he started writing about the Fabricated Man he was
drawing very explicitly and in opposition to what he thought were bad
developments. Someone like Leon Kass, I think, draws very heavily on the
religious tradition. One of the reasons he got clobbered so much by Joe Fletcher
was that he wasn’t as precise about it, or perhaps as open about what he was
doing. The other problem the Commission, NBAC, faced on cloning was once
you get to the point of saying, “Okay, there are insights here, and there are things
that connect with a philosophical analysis or other analyses that are not sectarian,
and are in certain ways secular, but some of them are almost -- intuitive is too
strong a word -- but they’re sort of ‘this doesn’t feel right.’ Now how do we help
to explain why it doesn’t feel right?” The problem is, if you translate or try to put in more secular terms the arguments that the religious people made, have you debased them? Do you get to the point where it’s worse to rely on them because you haven’t kept them in the terms that they themselves use. The chapter on religion in the cloning report was crucial. Jim Childress was its primary author, but it was the chapter that I edited most heavily. It’s odd that I did, but I pushed Jim very hard and reorganized the chapter. Jim did a very nice job with it. He didn’t abandon the explanations, but what he did was connect them to the sense of human integrity and dignity and so forth. These are concepts which speak to people who have no religious affiliation, who don’t have to believe that man was made in the image of God to think that you ought not to do things that debase human beings. Then you get to the question, “Does cloning debase?” That’s a separate issue. It would have been different if we had tried to argue that cloning was right or wrong based on the Book of Genesis solely. If you look around and say, “Is this what God was doing? Are we God’s co-creators?, and if we are those kinds then cloning would be fine.” That kind of lock-step logic directly from a biblical source to a policy conclusion.

SWAZY: That would not fly.

CAPRON: It would not. But I think it turns out that you can help people because many of us, whatever our religious views are, have that tradition, or are aware of it and aware
that it has something to teach us.

Anyway, I think that religion has been less prominent in bioethics in part because of the public policy issues and the existence of the public bioethics of the National Commission, the President’s Commission, and NBAC. But that’s not the whole explanation. I think part of it is that religious people have felt that it’s somehow embarrassing to talk solely in religious terms, that they make themselves more credible if they talk as though they weren’t religious people, if they were just secular. And it may be, and this is the part I can’t answer, that within the schools of theology there are other issues that are preoccupying the academics. So you simply have no real replacement for a Paul Ramsey. Some of the other people you mentioned...Jim Gustafson...Bill May. We have a Bill May on this campus. He’s a colleague here in the school of religion and is one of the remaining people on the campus who is very active in social ethics and is still trying to carve out something in bioethics. But the other Bill May, now from Texas, wrote some of the most interesting pieces on religion and bioethics. In fact, when I was asked to contribute a piece on the first 20 years of The Hastings Center Report and to pick out an article that I thought was particularly influential and important, I picked out one by Bill May about “The Newly Dead,” in which he didn’t just go to the Bible but also went to other religious traditions. But who are the major theologians today involved with the Hastings Center or involved
even at the Kennedy Institute? Think of the people at the Kennedy Institute, Beauchamp, Veatch, LeRoy Walters. LeRoy is more into the federal side of things, like chairing the RAC, and is forever coming up with tables that show what every country has done, very useful, interesting stuff but it’s not religious. And he contrasts not just with Pellegrino when he was there, and with Andre Hellegers himself, who was, I think, very religious. It’s quite remarkable; I hadn’t thought about it before. Kennedy may have two or three very strong theologians whose work I just don’t know.

SWAZEY: But the point is names don’t leap to one’s mind.

CAPRON: No. Yesterday evening my mother-in-law was quoting this thing from The LA Times which was talking about the American Film Institute and she read off the films that were made in 1939, Nanoshka, Wuthering Heights, The Wizard of Oz, Mr. Smith Goes to Washington. It’s a list of ten films that could’ve been the list of the ten greatest films of all times, just in 1939. And you can barely name their equivalents today, they don’t exist. I think it’s the same as saying McCormick, Gustafson, Ramsey, Fletcher, May. Their like hasn’t been found.

Yesterday when I was mentioning the staff at the Hastings Center, I said that I recognize there’s always the danger, particularly for those of us who were young then, that these older figures with their experience and their years of scholarship seemed like giants. It’s like when you go as a freshman to a college,
and the seniors are all giants, but you get to be a senior and there are no giants around because they’re just you and your friends. And yet, there are freshmen looking at you thinking the same thing. So, I recognize that there is that risk but I just don’t see the interest from the religious side.

SWAZEY: Let me switch briefly to social science. You certainly strike me as someone who’s always had a very strong social perspective. And obviously with the work you’re doing at the Pacific Center, you think social science research is important. I’d say that rather puts you out of the mainstream among bioethicists. What’s your perspective on why there’s been such a strong tension between bioethics and the social sciences?

CAPRON: That’s a good question. I don’t think it’s inherent. I don’t have a good answer for it. I think in any field there is a tension between those who would like to theorize and those who insist that the more painstaking work of developing observations and data ought to come in to the picture. It may have been that there were relatively few social scientists who found either the questions that bioethics was asking, or the support available to help them ask more interesting questions, to be adequate to engage them. Among the social scientists, someone like Renée, who is so much on the qualitative side and the nuanced examination of the social situations, rather than the quantitative, might have found things more friendly.

But she also, I think, found a relative lack of interest. I don’t have the full
SWAZEY: In your paper for Arthur Kleinman’s conference, you discuss the law and policies and why policy is made in the absence of or despite data. I think you made the point that when you are drawing primarily on more abstract theoretical principles there isn’t that much room for or interest in social science. Do you think that translates into the general philosophical approach to bioethics?

CAPRON: Yes, certainly the principlists, as opposed to say the phenomenologists among the philosophers, would be inclined to think that the data are relatively unimportant because the principle leads you to the conclusion. I guess my lawyer side, combined with some of the psychoanalytic skepticism about reality as people simply describe it or as it’s structured, leaves me thinking that the devil is in the details in a lot of this stuff, and you’ve got to study the details. When I started out at Penn, being interested in what people in genetics were doing even before I got there because of my involvement with people at Yale and at Hastings, I was very comfortable dealing with the policy issues and screening and so forth. But I realized that with genetic counseling you really had to know what the counselors did. So I went to the literature, and there was just nothing, which was why I then, with Renée said, “Well, we’ve got to do field work.” And I became a participant observer. We recognized the need for someone who was going to have more time just to do that kind of thing, and that’s when we got a grant and hired Charles
Bosk. The relatively limited couple years of observation that I was doing certainly informed my work even though it didn’t amount to independently published social science papers. It was not intended to be quantitative; what I wanted to do was to try to pick up on things that you wouldn’t necessarily know exist in the relationship between geneticists and families.

SWAZEY: You have to look at the lived-in reality of what’s happening.

CAPRON: Exactly. It seemed to me then that if there were going to be policies that said this or that rule on confidentiality should apply, or this and that form of consent is what we need, they ought to be based on what the real interactions were like and where problems, and risks, and tensions existed. As I say, that wasn’t in the literature at the time, but thanks to Bosk and others now it is.

I should add that the particular Pacific Center social science project that I described, we pray that we can get funding for. It’s a big project, and one of the issues I think in the bioethics field is that bioethics is otherwise pretty cheap to do.

You just set someone down in a library and have them read and write. Maybe they go out and talk to a few people, but it’s pretty cheap. The kind of thing we’re doing, where you have 500-plus subjects and are doing a probability sample and so on, is very expensive by bioethics terms.

SWAZEY: I know it is!

CAPRON: So I think that’s one of the reasons why it doesn’t get done. I believe in full range
of social science techniques are appropriate for bioethics. As you do your study it
would be very interesting to see if there is an answer to what the barriers have
been. It may have been that the phenomenon being studied, unlike the outcomes
of medical interventions or research interventions, were considered too soft by the
NIH people so they probably weren’t interested in funding it. And the people who
fund social science research may not have seen the questions as being as pressing
as people looking at questions of racism, poverty, drugs, and the city. In other
words, if you look at where money was going for sociologists to do all sorts of
kinds of work, it may have been that 10 or 20 or 30 years ago, those issues that
bioethics was looking at were seen as too peripheral, too esoteric.

SWAZEY: I’m not sure it was as much a lack of funding interest as a lack of a sense by some
of the major people at centers like Hastings that social science perspectives and
research had anything to bring to the table. I think this was partly due to the rise
of principlism and analytic philosophy sort of running the show. There was a
sense that sort of lived-in reality that we’re talking about wasn’t needed. I
remember an early Hastings Center Task Force on neonatal intensive care, which I
was on for a while. I got to the first meeting and looked around the table and said,
“There aren’t any neonatologists here...physicians or nurses.” The response was,
“We have physicians. Will Gaylin and Bob Morrison are members of the group.”
My thought was, they are wonderful people but they’re not neonatologists! So it
was just sort of a disinterest. I think that may be somewhat starting to change now, but I’m not sure that the sudden interest in narratives and so forth is the same. I guess time will tell.

CAPRON: Yes, I don’t think it is quite the same. I also don’t think that having a few individuals from a field amounts to supporting the work of social scientists to tell us things that even the participants don’t know about the field. When you write about the artificial heart or something, you’re telling DeVries and Cooley and other people things that they don’t know. It’s not as if you can get them in the room and they can tell you everything that’s there; they don’t know it until you’ve studied it. I don’t think that it’s something that has an easy equivalent. It is a lamentable missing piece.

SWAZEY: I think both sides have lost out and it’s too bad. Let me shift to law, a topic you know much about. I thought your discussion of law and of jurisprudential approaches to philosophy in bioethics in the paper you did for Kleinman’s conference was superb. Let me ask you the flip side. We talked about what law has contributed to bioethics, is there a converse relationship? Has bioethics contributed to law?

CAPRON: Well, there are two ways of looking at law in this context. One is the development of the laws themselves. The other is the part of law that I deal with, which is teaching law. Let’s take the latter first. For a lot of students and for a lot
of people who write in the field from law, the kinds of dilemmas and issues that are generated in the area that is usually denominated bioethics, present, in very, very immediate and very real ways, some of the basic issues that the law, as a means by which society mediates conflicts and organizes activity, and attempts to achieve some state of human flourishing and a world that is good to live in, has dealt with since time immemorial. There are other ways in which our society confronts those issues, when we look at racial differences, when we look at poverty, when we look at a range of other difficult social questions. But what is remarkable about the things that bioethics deals with is that probably every person confronts those issues, sometimes directly in his or her own life or in lives indirectly through relatives. And so it is something which has that importance, that immediacy, and that inevitability, that makes it a way of focusing discussion and attention. My impression, not having studied the whole curriculum, is that law professors teaching contracts will draw on issues in medical care today because they raise very interesting issues. We have a course a first year course that is very unusual, called Law, Language, and Ethics, not bioethics. It is basically an examination of values in society. I have the impression from my colleagues who come to get cases and ideas from me for the course that they often find that bioethics has a set of issues that help focus and illuminate problems. If you are talking about problems of scarcity you can make up a desert island and put
people on it, or you can talk about dialysis machines in 1972, or you can talk
about access to an AIDS drug which was “promising” and the only way to get it is
to go into a research study. And then what happens if it’s placebo controlled and
all the subjects in the research get together every week and put all the pills in a
barrel and just draw out their supply so that they all have an equal chance of
going an effective pill and ruin the research design?

SWAZEY: You don’t need the desert island!

CAPRON: You don’t need the desert island! Bioethics has every major issue of human
freedom, of what it means to be a Kantian agent, willing something. It stops
being abstract and starts being real when you look at the things we look at. I’m
sure that for myself one of the reasons I moved from civil rights and my concerns
there to the issues of bioethics, beyond the fact that I was serendipitously drawn
into working on them, was that they felt so compelling because they seemed to
raise the same issues of justice, and fairness, and human choice, and human
agency, in a way that was infinitely fascinating and varied. And increasingly, you
didn’t have to draw from analogies because there were plenty of cases right in the
field to use, plenty of statutes and so forth. So I think that on that level bioethics
has enriched law. On the public level, it’s some of the same sort of thing. The
cases and issues that present the dilemmas of the Quinlan case, the Cruzan case,
have been important for getting people to realize that we need, through the law, to
address these issues. Come up with a durable power of attorney for health care,
and so forth.

I don't know if it's had the same heuristic effect for society as a whole,
I'm not enough of a sociologist to know that. That is to say, has thinking about
cloning, or surrogate motherhood, or advertising to college students to become
egg donors, has that helped society to ask questions that are more basic, more
generalized? I don't know. I suspect that legislators and judges have learned
from what they've read in articles and briefs and applied to their own lives. I was
working on a grant with someone here, a collaboration we're setting up to try to
use something called The Hollywood Health Partnership, which is made up of
congregations and schools in Hollywood. If you know Los Angeles, it's not a
glamorous neighborhood. It's fairly poor and very ethnically diverse with a lot of
Asian immigrants, and Armenian, Eastern European, and Latin American
residents. We want to use the partnership to educate people through parish nurses
about the issues of the end of life, and about palliative care, pain control, and so
forth. The person I was working with called me a few weeks ago and he said,
"You know, that was such an educational experience for me. In the interim, my
wife’s mother got very sick and died. And what I learned from you in talking
about how we were going to frame the issues and what our educational objectives
are, was enormously helpful and influential in how we responded to my mother-
in-law’s illness. I just wanted to thank you for that.” It was an unexpected side
effect. I was pleased at that. But I don’t know the extent to which people, in
thinking about a whole range of other things, may have been influenced by
bioethics. Clearly, bioethics has resulted in a lot of law being made by courts and
legislators and the like, as rules have been developed about human subject
research, and the determination of death, and organ transplantation. Not as many
yet as we probably need well thought through on reproductive technologies which,
because it’s tied up a little bit with the abortion debate, has been a very hot potato.
And also because, I think, we just don’t know what we want to do about that. I
mean the tension there between the infertility lobby on the one hand and the
people who would regard it as an abomination to make any altering -- sort of a
Paul Ramsey position that children come out of a marriage relationship and
intercourse and that using test tubes, even with a sperm and egg of a couple, is a
violation of that covenant.

SWAZEY: I think we’re still figuring out what questions we should be asking.

CAPRON: Right, and that range of issues is very poorly resolved. But overall yes, I think
bioethics has influenced laws and regulation. If you look at the law as it relates to
health care institutions and how they behave, institutions, bioethics shows itself in
the things that the Joint Commission surveyors look for when they go to hospitals
now. They have expectations and scorable guidelines on how the institution deals
with ethical issues. So it’s had an effect.

SWAZEY: Akin to the question of who are the major theologians today, as you think about a younger generation coming up in bioethics, are there people that you would single out and say these people are going to have an impact down the pike?

CAPRON: You know, it’s an interesting question. I recently found myself talking with Dan Wikler and Norm Daniels and a couple of other people about this, and then with Eric Meslin about it as well. Eric is an example of someone in the younger generation and is in the position that I was in almost twenty years ago, of trying to gather together leading people to staff NBAC, something that you really need to have a successful commission. For whatever reason, it really does seem as though there hasn’t been as much of a next generation as one would expect, particularly on the philosophical side. It’s not a matter of exalting them, but we had the generation of the Daniels and the Wiklers and the Buchanans, and the Brocks. I’m going to leave out 5 or 10 others, I’m sure. On the legal side, there are a lot more people writing in bioethics than there used to be among young lawyers and law professors. Susan Wolf is a younger generation and she’s extremely good. There are also people from other fields, who are not younger but whose writing on law and medicine or law and health care, brings in a lot of bioethics -- people like Rand Rosenblatt and Sylvia Law. There’s just a shelf full of law books, of case books now, that deal with law and medicine and have a big chunk on the ethical
issues of health care. This wasn’t true when the main book in the field was Bill Currans’s book, which really didn’t have a lot bioethics. It was much more of a traditional forensic medicine plus health care organization.

I think there is a risk that we don’t yet know who the people are who would be the most important contributors. When bioethics wasn’t a field, you had to be adventuresome to come out of philosophy, or medicine, or nursing, or law, or social science, to work in it. There was a sense of newness and excitement and you weren’t spending your time reading the literature, you were spending your time writing the literature. Certainly a situation in which I’m always more comfortable -- writing. (Laughter) It may just be that it attracted a different group of people, and now that it’s more established the people who are attracted to a frontier are off on that frontier, and it’s no longer bioethics as much. Among the people who are still attracted to it there will be any number who, in a longer historical perspective, will turn out to be as important in making contributions.

But it probably gets, for them, harder and harder to do that if so much of the foundational work is done, and if the field operates, as it seems to, so much in arguments around basic principles and so forth. If this were nuclear physics then even after Einstein someone can do, on the experimental level, something which is of Nobel quality even if what they are doing is proving that Einstein’s theory plays out in the real world. But it’s different when you’re dealing with something
like bioethics, where there is so little of that breakthrough experimentation that can be done, where so much of it is revisiting the issue of respect for persons or the like, and where you've got Paul Ramsey and Jim Childress and Tom Beauchamp having written about that subject with insight and nuance and so forth, what more are you going to say? I think that may be true for those of us in the field. I think one of the reasons I remain a generalist and write about a lot of subjects is that what often interests me are particular twists and turns that haven't been looked at, as opposed to being more encyclopedic. The one area that I write about with regularity and always find myself challenged to ask myself, what I can say that's new, is the determination of death. One of the things that was most enjoyable for me was in the first edition of Bob Veatch's book that's intended as a reader, where he had a number of us write on different things. I wrote on human experimentation. When I sat down to write I thought, "what am I going to say about it? I've been writing about this for twenty years!" This was before the publicity about the radiation experiments so there weren't a lot of sudden new revelations to have. Bob said he loved the chapter, and I got so many compliments on it. It was very refreshing for me to discover that I could write about something which I'd been thinking about and writing about for a long time, in a way that struck people into saying new things that they hadn't seen.

SWAZEY: Also reaching new audiences.
CAPRON:  Yes, but I can't hit the new audiences by writing the review article. I admire people who can do this, I'm not good at that because I really don't enjoy spending endless amounts of time reading other peoples' writings and then pointing out the issues. Of the three articles I wrote for the second edition of the Encyclopedia, “The Determination of Death” a review article, but it's something I'm so saturated with that I didn't mind doing it. The other was “The Law and Bioethics.” I just wrote that, and it felt to me like I could think about the subject and write where my analysis led me. Yes, I read half a dozen peoples’ things on it but I didn’t attempt to do a review. The thing that was closest to writing a review was the piece I had to do on public policy about end of life issues, and that was the least interesting for me to do. It may be that if you are dealing with a field where there are volumes and volumes on everything a lot of what the young people coming along have to do is write the review articles and maybe add their own fillip on it here or there. That isn't as exciting a task for people. I don't know if that's one of the reasons why you look around and say, “Who's doing really interesting work today?” Maybe the people are just as bright but the topic doesn't lend itself to a wild idea like Will Gaylin's bioemporium filled with neomorts. That flight of fancy has already been taken. And, in any case, writing like that doesn't lend itself to a Principles of Biomedical Ethics!

SWAZEY:  How much new is there?
How much new is there? There are five major competing basic books on economics that are used by students. You can write one in a somewhat new approach or make it a problems-oriented book. There are things you can do but Samuelson’s still sits there. He did it! He was the modern post-Keynesian, post-war economics textbook. The people that came along after that were sort of fiddling...I’m on thin ice here because I gather that there are now one or two people whose books are pushing Samuelson aside. So the life of Samuelson may be over as the major book. But for a long time that was true in that field. I have a sense that may be true of bioethics and it may help to explain why we don’t think of the field as having as many great people today. You know, it was partly because Richard McCormick, and Jim Gustafson, and Paul Ramsey were great men before they came to bioethics. They had already written wonderful things; they brought people like Bob Morrison in bioethics. These were all people who had made great contributions in their own field, were recognized and had stature. For them to concern themselves with the issues of bioethics almost legitimated the field, as a field that would reward careful study and thought. But they brought to it a lot. If we’re now dealing with people who see themselves as BA’s, MA’s, and PhD’s in bioethics, they don’t have that breadth, just inherently, of coming in from another discipline. So that may also be at work here.

That’s a very insightful perspectives. If we were sitting here in 20 or 30 years,
what will bioethics be like? Is there going to be a bioethics field?

CAPRON: I'm not a futurologist, I'm not good at these kinds of questions. The field has been around 30 years, and many of the issues that we talked about back then are still around.

SWAZEY: They don't seem to go away.

CAPRON: I've joked about the fact that we must be doing a pretty bad job because we haven't solved any of the problems, which isn't entirely true. I think in many ways there have been reasonable solutions.

SWAZEY: Forecasting is an imprecise art at best, but you've talked about some things that you think are affecting bioethics now, like the drive to professionalization which may diminish the field's diversity and the fact that the founders did the foundational work. So would you envision a different type of bioethics as the next couple of decades unfold? Is it going to be doing different things?

CAPRON: I suspect that there will be a lot more institutional bioethics, that is to say, hospitals and the like. The bioethicists will then be in a position of some risk of becoming corporate apologists, as it were.

SWAZEY: Like the corporate ethicists.

CAPRON: Yes. The origins of bioethics, at least in part I think, are with the empowerments of various groups and the "isms," consumerism and so forth, that mark the end of the 1960's and into the early 1970's. A lot of what bioethics did, or bioethicists,
was attack the status quo, usually not too harshly or too stridently but often quite strongly. They called attention to problems of patients not being treated respectfully, being subjected to end of life care and CPR inappropriately, and human subjects being abused. Prisoners and minorities, women and children were particularly badly used and so forth. So there was a very strong critical stance for bioethics. I think that’s another reason why it took some fairly unusual physicians to be the people who joined in the bioethics movement, if you want to call it that, looking at it as a social movement, because they were amongst people who were, in effect, attacking the way their field was being practiced. That, I think, is much less a characteristic of today than it was then. I sometimes think of myself as an old curmudgeon because, so often these days, I find myself in the position of saying, “No, I don’t think so” to the latest development of something. I think what people today want, and it’s part of that paradigm shift in research, is much less protection from the harms that earlier generations thought medicine might be doing and more access. Even the strong criticisms against HMO’s includes the criticism of the HMO standing in the way of access to research, or to particular kinds of care at the end of life, or to pain control, or access to reproductive technologies, and to experimental bone marrow transplants for breast cancer. The list goes on and on. So that stance has changed, and now if the bioethicist weighs in it may be to say, “Well, wait a second, is that a good use of resources? What
does that imply for the products of conception, etc, etc?” Those kinds of
questions are raised. And the other bioethicists are working for the health care
institution, trying to facilitate the institution as they apply end of life care, and
making sure that the advanced directives get signed, and that the ethics committee
meets, and that business can be conducted. I do suspect that as the field gets
professionalized and as we turn out more graduates who have the name or title
bioethicist, they’ll be working for hospitals, and nursing homes, and HMO’s, and
so forth.

SWAZEY: Do you think there’ll be a shift, which is another point you made in your Harvard
paper and elsewhere, in bioethics’ focus on process and procedures to more of the
emphasis on the morality of the decisions?

CAPRON: I don’t know. Certainly to the extent that the public commissions have a role
their focus is likely to remain on process and procedure. While you can read
“Deciding to Forego Life Sustaining Treatment” from the President’s Commission
and say it has guidance in it about better and worse kinds of decision making,
most of it is and should be on process and procedure. It’s dealing with people
who bring such an array of individual values and religious traditions and so forth
to their own decision making that it would be inappropriate to say, “Well, because
your religion teaches you that as long as there is breath there is a life worth
protecting, and yours says no, it depends upon the quality of the interaction, then
you’re right and you’re wrong.” That would not be appropriate for a public
commission. And since so much of what we now think of as bioethics, and the
most prominent visible forms of bioethics, are the operations of the public
commissions, I think the proceduralism is not going to go away. If out of the
religious traditions and elsewhere more people came to the field who are willing
to write, not as secularists talking about general principles and general policies,
but instead as people committed to a certain view of what is good in the world and
the responsibilities that people have to act a certain fashion, yes. Then we might
have more direct argumentation, and guidance, and conclusions about how one
ought to respond as an individual or as a professional, not procedurally but
substantively, to a dilemma about life or birth or illness. I haven’t seen that
emerge yet, but it’s something I would like to see emerge. I think bioethics would
be both richer for it and more relevant to people’s lives. There is a limit to how
much you can tell people if you’re simply telling them, “Well, fill out the form
and just have it say whatever you want it to say.” Yes, that’s valuable, but
suppose you have a broken leg and ask the doctor “Well, which procedure would
probably work best in this circumstance if I want to go back to playing football?”
If the doctor said, “Well, I told you the procedures, you pick,” you would feel
“No, I expect some guidance. I expect some benefit of thought prior to this.”

SWAZEY: I think one place where that is the normative mode of doing things is in Jewish
medical ethics, because it is guided by Jewish law.

CAPRON: Yes, and I think it has a place in a certain amount of the Catholic religion as well.

I was thinking about one thing that we talked about yesterday, and that was this label of “the public intellectual.” I came to the following sort of tentative thought about that. And I was thinking of it also in light of the fact that we had gotten to that talking about Art Caplan. I guess I would say that Art is....

SWAZEY: Actually, we got talking about it with respect to Alex Capron.

CAPRON: Yes, but in any case, I think without question Art is America’s most widely quoted bioethicist. And if you ask me to characterize myself, it would not be in the role of the public intellectual, which I don’t think the public is looking for, frankly. I guess I feel as though I’ve been the person who’s been most connected to the institutional public bioethics through my Commission roles. It’s the same way I think that we say of Callahan and Gaylin, that they are the people who made the biggest contribution to the emergence of the field as something deserving the kind of interdisciplinary study that the Hastings Center promoted. You could make the characterization of what Hellegers did, although he didn’t live that long into it, but Pellegrino did, and then Veatch and Beauchamp, and so forth, at Kennedy. It just happens, I think, that the role that I’ve had is not one for which the phrase “public intellectual” fits, though I suppose if you’re an academic to be called an intellectual is a nice compliment. The kind of objectives that I had with
the President’s Commission was to deal with the topics we looked at in a way which would be useful to and certainly accepted by and respected by the experts in the field, but which also tried to speak in a way that was accessible to intelligent citizens because these are issues that are important to all of us. They are not issues to be talked about behind closed doors in hospitals, or in research ethics committees. They are not issues that only concern the kind of legislative draftspersons who are writing the technical requirements for the uniform commercial code or something. They’re not matters which only belong in churches. They are not matters simply for individual sectarian examination, because we live in a society together where we bump up against these issues. We all have to have a way of understanding and negotiating around our differences as the decisions are made. Here is an attempt, in a very public way, not the ten page report. When we got some of our original Reagan Commissioners, they included a couple of people who had been very active in medicine, including Dr. Dunlop. His first reaction, at the time of his first meeting he said, “What is this? You have a briefing book this thick!” By then, as they came in, we were in midstream with several reports. I assume that the briefing book had a couple of drafts of either reports or chapters of reports. And he said, “Why are these so long? Why aren’t these the two or three, or five-page things?” that he was used to seeing in medicine and surgery. In time he became one of the strongest Commissioners and
one of the fans of what we were doing, because he saw that you aren’t speaking in
shorthand to colleagues in the field where you’ve narrowed things down and
you’re just addressing them. You really have to get the context and the way this
comes about, and how different people have struggled with it, and so forth. That I
think is an important distinction about a successful public bioethics. It’s different
than writing in the academic journals. It’s also different than writing on Capitol
Hill, something that is a purely political document. One of the great things was
the decision in America to be the first country to do it this way, to have these
publicly chartered, publicly constituted, bodies with members of the public, not
politicians, and to be publicly accessible both in their meetings and through
dealings with the media and the issuance of reports. Having commissions to deal
with these kinds of issues was to say these are ones which the pure, old-fashioned
political process doesn’t deal with very well. We don’t have the attention span in
Congress to spend several years on this kind of thing. We don’t have the distance
to be able to step back from the jockeying for position, which is why in the end
the BEAC was such a failure because it was too close to that process. I think the
miracle of the OTA was that it operated as much as it did, but even that was
intended to be outside the congressional committee process. You know when a
committee requests a study on the supersonic transport, for example, it’s not going
to just be done by the Transportation or Interstate Commerce Committee or
something. The same was true of the bioethics commissions. The advantage I think that the President's Commission had, and maybe the present Commission can have, is not having just a narrow subset of topics but have ones which interact and interconnect in ways that maybe can't be all sketched out at first, but where there is some responsibility to say consistent things. Don't apply a totally different set of principles in looking at human experimentation than you do in access to health care; they are connected and they are all part of a system. That's where I've tried to devote my effort and been fortunate -- though with BEAC, perhaps you would say unfortunate -- to have had that opportunity. As well as on the RAC and other advisory committees.

The RAC in some ways was one of the most interesting advising committees I've been on since it was such a long experience, going over a decade, and also one where you once again saw the difficulties of doing human subjects research. What we were looking at was gene therapy, which was appropriately named because it was therapy on the gene, but it was all research. And of course the title "gene therapy," I'm sure, contributed to a lot of peoples' confusion as to what they were being asked to engage in in a field which still isn't clear yet and has not produced much of any therapeutic modality. The idea that it will become therapeutic is fine, but it still is basically research on genetic manipulation of human cells, though that's too clumsy a title. Anyway, I was thinking last night
about why I had dragged my feet on the “public intellectual” characterization.

SWAZEY: That’s a very thoughtful reformulation.

CAPRON: I hope that’s helpful.

SWAZEY: That is very helpful.

END OF INTERVIEW