Swazey: Let me start out with something we’ll come back to, but since you are one of the major figures in bioethics, I’d like to know how you think about bioethics, how would you characterize it?

Jonsen: I think of it both as a discipline and a discourse. Discourse first: I think that the way this field has developed, it’s been very largely people talking to people. It’s been an increasingly extended conversation among health care providers, scholars in other fields, and to some extent patients, and certainly the news media and so forth. It’s been a broadening conversation about a range of topics that are loosely clustered around the technologies of medicine, and the provision of health care, and the biological sciences as they develop. I use the word “discourse” to talk about a conversation that’s been given a certain shape. Conversations are given shape by certain words becoming more common within them, by those words acquiring general but specific definitions and by the arguments that take place within that conversation having a certain structure of pros and cons. It seems to me that this has been, for the past thirty years, a conversation which has shaped into a discourse around the topics. For example, one can almost now predict the way in which, a political debate over assisted suicide will go. We know the issues
that will be brought up, we know the arguments over terminology that will arise
and so forth.

That then leads to my second characterization of bioethics. It is a
discipline. There has been, of course, a debate since its beginnings: whether
bioethics ought to be called a discipline. Dan Callahan's early article in the
1970's uses the term "bioethics as a discipline," and he gives some characteristics
of a discipline in that article. I think that it's appropriate to call it a discipline in a
loose academic sense. There really aren't any disciplines in the old, formal sense
anymore in academia. Even mathematics, classical discipline, is now splintered
into all sorts of special fields. So I don't think we need to have a very strict
definition of a discipline. A discipline, to me, basically is a "teachable,"...which
is its literal, etymological meaning. A "teachable" means that a group of people
called professors can designate a beginning, middle, and an end to a set of
arguments and data. I think that has come into shape. It bulges at the edges, or it
leaks at the edges, there's no doubt about that, but it's the way in which
mathematics leaks into physics and physics leaks into mathematics. It's
teachable, one knows now what to do when one walks into a classroom with a
course description that says bioethics.

Swazey: Do you think that was equally true when Dan wrote about it in the early 1970's?
Jonsen: No, it was not true then. Dan’s article talks about the future, bioethics becoming a discipline rather than being a discipline. I forget exactly the characterizations he gave of a discipline. I also think, along with teachability, a discipline has research ability. The people who teach it want to expand and deepen their understanding of the topics and the terms. They set out projects to refine that more completely and, although those projects are not like a scientific protocol, some people do historical research, some people do sociological research, some people do quasi-epidemiological research about such things as “do not resuscitate orders.” So Bioethics is a discipline in the sense that it’s a teachable subject and it has a research dimension to it. The ultimate proof of a discipline being a discipline is that somebody pays professors to teach it. So that’s my general characterization of the field.

Swazey: When would you say it reached that status?

Jonsen: I’d say it probably reached that status in the late 1970’s, early 1980’s. It was by that time that many medical schools had employed faculty to teach this subject, my primary criterion. At least there were enough teachers around that we could communicate with each other and associate with each other. I think that the Society for Health and Human Values started its faculty interest group just about that time. So there was a critical mass of teachers then. The appearance of The
Encyclopedia of Bioethics, several years previously, in 1976 laid out the body of topics. There were a few textbooks: Gorovitz’s text was out, Howard Brody’s text was out, Beachamp’s and Childress’ book appeared about 1979. And then there was also growing interest in bioethics being taught in other places, medical schools, university curriculum, in various departments like philosophy departments, and some social science and sociology departments. So that’s the point where some of these critical elements of disciplinary emerged. That was just about the time that Hastings had a task force on the teaching of bioethics. The interesting thing about that task force was that it examined not just the teaching in medical schools where it was most prominent, but also teaching in high schools, teaching in universities and so forth.

Swazey: While on that general theme, what’s your view about degree programs in bioethics?

Jonsen: Well, I started teaching in 1972 at UCSF. I was always very hesitant and quite skeptical about degree programs. That’s largely because I didn’t see bioethics as a discipline on its own because, in those days, I had a more formal definition of discipline. To me, it looked like it was an amalgam of philosophy, and theology, and sociology, and the biomedical stuff. I thought at the time, that of all of those bioethics should really be philosophy. That was my original prejudice. Therefore,
people ought to get philosophy degrees and then learn something about medicine
in its practice and its social structures. I gradually changed my mind on that, first
of all because my understanding of discipline loosened up a lot. That probably
was just about the time I came to the University of Washington which was 1987.

Another point about the previous issue is that I’ve always thought of bioethics
largely as an adjunct to other activities in those days.

Swazey: For you professionally, or just in general?

Jonsen: In general. That it was to help doctors and patients. Therefore I didn’t want it to
take on a life of its own. Now if one can talk of a mild conversion--this is not
Paul struck on the way to Tarsus--when I came here I inherited a degree program
that was, at that time, actually history of medicine but had mutated into ethics
because students were interested in it. They were taking history MA work while
really doing bioethics. So I inherited a degree program and I also came back into
a university because UCSF, as you know, is a truncated university, really a health
sciences research center. At UW, I was back in a university, in actual contact with
other disciplines, with history and philosophy and sociology. I was beginning to
get more liberal about what a discipline was. So just in terms of my actually
having a degree program at my finger tips here, and in terms of liberalization of
my disciplinary concept, I began to think that a degree program was a useful thing.
At the same time other people were mounting degree programs fairly successfully. I’d been impressed at what Georgetown was doing. Between UCSF and UW, I spent a semester teaching at Georgetown before I came here, teaching in their doctoral program. I thought that they had arranged things pretty well, that they had a mix of philosophy and other disciplines. As I look back on it, it was probably too philosophical.

Swazey: This was their intensive course?

Jansen: No, this was their graduate program, which was in the philosophy department. I taught for a semester and gave two courses to graduate students. So my judgement now is that things have matured to the point where bioethics can be appropriately thought of as a degree program. I still am rather skeptical about a PhD for most interested students I think the PhD’s, for people who are working in bioethics, with a strong concentration on ought to be in classical disciplines and a concentration in bioethics. But in particular, I’m beginning to think that the masters degree program is an appropriate thing for a variety of people who will not become professors, mostly people who are health professionals and others who will be administrators at HMO’s or research IRB coordinators, things of that sort. The masters program now reflects the level of complexity which the discipline has reached. There was a time when we could say, “Take the intensive
course and you’ll know enough about bioethics to be able to talk about it intelligently.” I think now the field is extensive enough and complex enough that a masters degree is an honest acknowledgment of the breadth of that complexity. And so for people who want to do that, that’s what we’ve done here. We’ve changed our masters program to one exclusively designed for professional people. It’s a little like an MPH in that respect. It’s a little like an MPH, that’s right. That’s exactly the parallel. In fact, what we were doing here for those professional people who wanted to do that more intensive involvement, was giving them an MPH. It was the only degree around that we could give them because our MA here was a heavily philosophically laden course. So a physician would come and say, “I want to spend a year doing this.” We had to give him an MPH in the school of public health with a big dose of bioethics. Actually they studied with us but they took the MPH degree. It’s really sort of a generalist degree. Yes. So we changed that two years ago and now we’re giving an MA to health professionals. Case Western does pretty much the same. I think Penn now is on the verge, or maybe they’ve already started.
They're just starting. Who's a bioethicist? I assume you define yourself as a bioethicist?

Yes, I do. I have a lot of fun with that, the origin of the word, where it came from and all the rest. It's fun to fiddle around with. I think a bioethicist is a person who is full-time employed doing the things that bioethics is. I think it's a pragmatic definition. There are probably 200-300 people who have full-time jobs either teaching, or counseling, or consulting. And their topics are broadly the topics of bioethics. So I don't have a very fancy definition.

Pragmatic in terms of if they're doing bioethically relevant things most of the time, then they are by definition a bioethicist?

Yes, it's an operational definition. I would exclude the physicians and nurses who studied the field and who, on occasion, consult. Let's take a concrete example. Over in Boise there's a chaplain in the hospital that is affiliated with the Episcopal Church, who has studied a lot of bioethics. She has come over here and taken our certificate program so forth and so on. She's a chaplain, that's what she is. She consults in bioethics; she's their bioethics person but her job description is the job description you would expect a chaplain to have. I wouldn't consider her a bioethicist. At Sacred Heart Hospital in Spokane there is a fellow who's a nurse
by training, named Johnny Cox, who is full-time employed as the ethics
consultant. He doesn't do any nursing anymore. He's a bioethicist. It's a job
description more than anything else. The reason I mentioned the chaplain is that
she's now trying to get her hospital to rewrite her job description to include a
substantial piece of bioethics consultation because she says, “That's the way my
career has moved. People come to me as much for bioethics consultation as they
do for spiritual advice and liturgical activities.”

Swazey: Why do you think so many people who are interested in the topics bioethics deals
with, and broad value questions, are defined and called a bioethicist no matter
what their field is?

Jonsen: I think that's in part a media phenomenon. The media has picked up on the term
“ethicist” or “bioethicist” and it's amazing to see it show up everywhere. Gina
Kolata's articles always have to have Arthur Caplan in there and Arthur is always
“ethicist.” Now Arthur is a real ethicist but if she gets somebody else...if she
came to you she would probably describe you as ethicist.

Swazey: Larry Altman and Phil Hilts and others have. I have worked on bioethical topics
for a long time and I'm always being introduced in Maine, given its small
population, as the state's senior bioethicist. I sort of look around to see who they
Jonsen: I wouldn’t say that you are a bioethicist because your general field of work is much, much broader than that. And Renée Fox is not a bioethicist. She is a social scientist.

Swazey: She is a social scientist who works on bioethical topics.

Jonsen: There’s also a certain caché about bioethicists, which probably is a result of the media’s use of the term. Art and others in the field are always downplaying the expertise aspect of it, saying that it’s silly to think that somebody has an expertise in ethics. I don’t think it’s silly at all. I think there are people who have a mastery of the kind of discourse I described earlier. As I said, you can anticipate how a conversation is going to go. Well, a non-expert doesn’t anticipate how that conversation is going to go, doesn’t know what the next move will be. I can sit in one of these debates, or discussions, or panels and listen to my previous speakers, and while they’re talking I create my response because I know what the moves are. That’s a form of expertise; I know how to play chess. What I don’t claim is that I can make a better ethical judgement than anybody else because in the last analysis ethical judgements are highly contingent and idiosyncratic. But I could probably say that when put to it, I can make a better informed ethical judgement.
than most other people. It may not be a better judgement, but it’s a form of
d electronics. I think that, even with the kind of skepticism and cynicism about
d electrical expertise, there is a belief that some people can say things about ethics that
are more sensible than other people.

Swazey: Where does a masters degree leave you in terms of that expertise? What are you
equipped to do? Can you be a clinical ethicist with a masters?

Jonsen: Yes, I think so.

Swazey: You sound a little unsure.

Jonsen: Well, being a clinical ethicist requires a good deal of personal skill.

Swazey: I want to get into that in some detail because I find that a fascinating phenomenon
in bioethics.

Jonsen: Yes, but I think a degree can give a person the tools. I think it can give them
enough information to be an advisor to an institution. For example, I think a
person might be asked to oversee an ethics committee, and so you know pretty
well what an ethics committee is when you have that sort of background. Two of
our graduates here have gone into IRB administration.

Swazey: Let me switch topics and get some of your professional history and entry into bioethics. Let’s go back to your training in theology and philosophy and see if you could broadly characterize the major dimensions of that training. For example, in philosophy, what kind of philosopher were you trained as?

Jonsen: This is pretty fully laid out in the preface of my book, *The Birth of Bioethics*. I entered the Jesuit Order in 1949 when I was 18 years old. In those days, the Jesuit education was a very rigorous and patterned education, traditionally extending over 13 years before ordination. In those days the Jesuits educated in the old fashion, in the Renaissance fashion. Students took a whole block of material without mixing it with other things. So we had 2 years of humanities, which were languages and literature. And then we spent three years in concentrated study in philosophy. During philosophy, they also taught a few other college subjects like physics and chemistry because in the Renaissance that was natural philosophy, so it was okay. We had modern physics, in addition to natural philosophy. In those days, (I’m talking of the very early 1950’s) the Jesuit course in philosophy was a course in what used to be called scholastic philosophy, which meant basically reading the major works of Aristotle and Thomas Aquinas. Aquinas, of course, is usually thought of as a theologian but he has major philosophical works that are
commentaries on Aristotle for the most part. So I was trained in what was a fairly narrow but very demanding system in which logic and rigor of argumentation, and carefulness with definition were considered very important. That happened to be an era in which there was an extraordinarily vital revitalization of scholastic philosophy. My teachers were trained with those people such as Jacques Maritan and Etienne Gilson, who were trying to take this medieval structure and relate it to modern thought, to make it come into contact with existentialism and with phenomenology. So we didn’t just read the Middle Ages, we were reading modern scholastic philosophy and modern philosophy.

Another feature of this modern scholasticism was a great interest in the history of philosophy. That was another dimension that was of great importance.

Swazey: The history of philosophy broadly defined, or history of scholasticism?

Jonsen: No, history of philosophy broadly defined. We read the pre-Socratics, we read Plato, we read Hobbes, Locke, Kant. I took a Kant seminar for a quarter and all this sort of thing. We had a solid foundation in a systematic philosophical approach and then we had quite a broad scope of the history of philosophy, so it was a very valuable three years. I think essentially those three years of philosophy were the equivalent of a PhD program, given the amount of work that we did. As soon as I finished that program in 1955, I was assigned by my Jesuit
superiors to teach philosophy. I taught philosophy at Loyola University in Los Angeles for three years. In teaching philosophy, of course, you don’t expose ordinary college students to the kind of expansive and rigorous stuff that we did but....

Swazey: Tempting as it was when you’re starting!

Jonsen: It took me time to break the mold, you know. Those were the days when there was a great deal of interest in existentialism. So I devised courses in philosophy, primarily in epistemology, and in ethics, that largely were the scholastic response to existentialism. That’s basically the way I taught. When I finished those three years I was sent back to the next phase of the Jesuit training which was four years of theology. Again, that was fundamentally scholastic theology but in that case it was amplified by the kind of biblical studies that were coming into focus at the time. Critical biblical studies in which archeology and linguistics and so forth were very important. That was the theological training which I think was also very rich and very rewarding.

I didn’t study much moral theology. There was a standard course in moral theology which we all had to take for two years, which I didn’t find very inspiring.

Well, I did find it inspiring in a negative sense because I realized that one of the important things for the Catholic Church was to revitalize their moral theology in
the same way that it was revitalizing its scriptural studies and its doctrinal
theology, which were the exciting subjects at that time. Moral theology was kind
of a backwater. So it was with that in mind that I began to inquire about the
possibility of doing some graduate studies that would help me participate in such
a task. In the world in which I was living, the standard way to do graduate study
would be to go to a Catholic University, such as Georgetown, Fordham, or St.
Louis University, or go to the Institute Catholique in Paris, or to go to the
Gregorian in Rome. I thought doing that would just leave me pretty much where I
was before.

Swazey: You didn’t quite know how to break out of that Catholic....

Jonsen: Yes, I didn’t know how to break out of that. But I did by chance learn about
Harvard’s summer school and I asked my superiors, in my second year of
theology, if I could go to Harvard’s summer school and take an ethics course.
They were liberal enough to allow me to do that. I went and I took the first course
that I had ever taken in metaethics, which wasn’t part of the Catholic discipline.
And I was really astonished by what metaethics was--basically an attempt to
analyze ethical language in a way that was somewhat parallel to what was going
on in biblical studies. You lift yourself up from the page and you say, “How are
these words functioning?” So I took that course and I took a course in the
sociology of religion. That was a fascinating course because the professor took as
his subject matter--I thought I was getting away from the Catholic world -- the
worker priests of France, a post-war phenomenon in France, within the social
world of French Catholicism. Absolutely fascinating course! I came back and I
really found myself changed by that summer school, and I asked if I could go back
the next year and they said yes. So I went back a second summer, took another
course in ethics. It wasn’t a very good course mainly a review of utilitarian
thinkers. And I took Victor Frankl’s course in logotherapy. He died recently; he
was a wonderful man. I had started to be, in a sense, secularized.

Swazey: Living in two different worlds...moving in two different worlds.

Jonsen: Yes! I was ordained in 1962 and it was our custom to have another year of
theology after that and then to have a year of retreat. I was sent to Montreal for
that year of retreat, which was supposed to be entirely devoted to religious and
spiritual things, but I was hooked now. When I was in Montreal, it was customary
during the period of Lent to go out and work in a church. I was in a French
speaking community and wasn’t ready to go to a Francophone parish, so I asked if
I could go down to the States and find a place. I tried to get the Harvard Catholic
Club but they didn’t have any place available. So I wrote to Yale’s St. Thomas
Moore House, and the chaplain there said, “Yes, come on down, I’d love to have
some help.” So I went down there and I met Professor Jim Gustafson. Then I
realized what I could do in graduate school because Gustafson was a genuinely
ecumenical figure. And I didn’t have to worry that I would be de-Catholicized.
He was very eager to have Catholic graduate students in religious studies focusing
on ethics. So I applied to Yale; I actually applied to the Harvard program at the
same time, got admitted to both on the same day. The Harvard program would
have been very different. Bob Veatch went through that program. It would’ve
been very different because there was little ecumenical interest at Harvard. The
professor of ethics there, James Luther Adams, was very much focused on the
Protestant reformation. I don’t think he would’ve known what to do with a
Catholic in that program. But the Yale program was absolutely marvelous for me
because it allowed me to explore my own tradition. In the course of the three
years I was at Yale, Gustafson had invited as visiting professors three of the most
distinguished Catholic thinkers of the time. Jesuit Robert Johann (he faded after a
while but at the time he was a big name) and Joseph Fuchs from Rome and
Bernard Härning. So I studied with each of them. Then I had a chance to explore
the Protestant tradition very fully. All of this was with ethics in mind, theological
ethics, but all of it was ethics. I was able to take a course from John Smith in
American pragmatism which also was a totally new experience for me, James and
Dewey in particular. I had, all the way through...this is a longer story than you
asked for, Judy!
Swazey: No, it is not! It is not any bit longer because one of the things I was going to specifically ask you about was your interactions with Jim Gustafson and what sort of influence he had on you. You are saying a great deal.

Jonsen: I will come back to Jim’s particular influence but I think that the general education that I got was extraordinarily fortunate because I was able to touch on almost all of the elements that go into modern bioethics long before bioethics was a glimmer on the horizon. I didn’t have to change a lot as I migrated into this field, in terms of the skills that I think are needed to do ethics. So I probably had the best education, the most relevant education, of anybody in the field, because it wasn’t focused within a particular discipline. For instance, Dan Callahan did a philosophy program at Harvard that was very disciplined but very limited.

Swazey: So you didn’t just study analytic philosophy or whatever the particular school was.

Jonsen: That’s right. And as you’ll see in The Birth of Bioethics, one of the fascinating things is that most of the philosophers who moved into the field came out of philosophy of science; almost nobody studied ethics because ethics was really a dead topic. Dan Clouser did concentrate on ethics at Harvard, and Tom Beauchamp did at Hopkins. Beauchamp didn’t do it exclusively, he was also very interested in epistemology. At any rate, none of the theologians had the
opportunity to do what I did outside the disciplinary field, except for the ones who
got to Yale such as Childress and Hauerwas that’s not really very accurate.
Veatch made his own way and really created a course for himself at Harvard. So
he’s probably as fortunate as I am in kind of making his own way. He actually
started with medical ethics in mind. He was interested in doing that before it
existed and trained himself step-by-step for it. But for the most part, other people
did pretty limited classical approaches to philosophy and theology. Should I talk
about Jim Gustafson now?

Swazey: Sure, that would be great.

Jonsen: As a teacher, he is really magisterial in the best sense. He draws his students in to
a problem in an extraordinary way. He never lectures at his graduate students; he
lectured when he taught undergraduates. I was his teaching assistant at the
Divinity School and he gave lectures of course. But with his graduate students it
was always how he could draw their minds into the problematic of the author that
we were reading. He insisted over and over again that we don’t overlay somebody
else’s thought with our own. What are they thinking and why are they thinking
what they’re thinking about in their social context, in their historical context, in
their personal context? That was a tremendous experience; the two-year seminar
that all the graduate students did with him was beautiful in that respect. He would
never let anybody say, “Well, in my view such and such is what Kierkegard is saying.” He would say, “We’re not really interested in your view. What is Kierkegard saying and why is he saying it the way he is?” And he drove us to that. We had a fabulous class! That particular year was Jim Childress and Stan Hauerwas and Jim Laney. Do you know Jim?

Swazey: No, I don’t.

Jonsen: Jim Laney didn’t go into ethics but almost immediately became dean of the divinity school at Emory and then its president. He was president at Emory for a number of years and he’s the one that brought Jim down to Emory. Then President Clinton appointed him Ambassador to Korea which he was for several years.

Swazey: And they were all in your group?

Jonsen: They were all in the seminar. That, in a sense, was the original cradle of bioethics, Childress and Hauerwas and myself in particular. We didn’t pay much attention to bioethical issues, we spent those two years largely reading the classics in the field of philosophical and theological ethics. We were having great debates in those days about the war. Paul Ramsey came up to Yale and defended the war.
Joe Fletcher came several times to lecture, to preside over our seminar as well. He had already published *Morals in Medicine* by that time and he was really pretty well into the world of medical ethics. But Jim Gustafson had that quality of being able to draw people out, and he had a very broad mastery of the literature in the field of ethics, historically and currently. I mean he could talk critically about something that was published yesterday and something that was published in the Middle Ages. Almost anything that you would say he would be able to put into a context. Thirdly, he was a very gentle man. He was very committed, probably the most thoroughly honest man I’ve ever encountered. Finally, the thing that made that experience very valuable was writing a dissertation with him; that’s where his honesty came out. He was a scrupulous reader of dissertations, and very honest, and could give directions. Once he had criticized what you had done, he could give directions for correction that were so helpful. I remember, for example, one point that most graduate students learn painfully that everybody learns at some point in time, but when I actually had him say it to me it was a huge insight. I wrote the first chapter in my dissertation and I started with the first author who’d ever written about it and went through serially.

Swazey: The student Rome to Roosevelt approach!

Jonsen: Yeah! That’s right! So I took the first chapter to him. He called me just a day or
so before Christmas; it was snowing and I went down to his office. He said, “This
is not a good beginning for the dissertation but it’s a good beginning for your
thinking about the dissertation. Now all of this material that you’ve got here,
you’ve got to turn it around and say, ‘what’s the issue that you want to pull out of
all of this stuff?’” Then he said, and this was the thing that struck me, “Almost
everything you have in this chapter should be in footnotes. The text shouldn’t be
cluttered with all this exposition.” He said, “Your readers should know that you
know that it’s all there, but that’s what a footnote is for.” And you go back and
you look at the draft and you start saying, “Oh yeah, I can scrap that.” And then
finally you get through all that and you say, “Ah, what’s left is what I want to
write about.” What’s the essential question?

Swazey: Which is not the way too many dissertations end up looking.

Jonsen: Oh no. And Jim really was helpful.

Swazey: I think mentoring is one of the most overused words in education, but do you
consider Jim a mentor?

Jonsen: Absolutely, yes. I think his influence on the field has been very great. He’s
mentored a lot of its faculty, I mean a lot of its members. A lot of them at
Chicago, such as Lisa Cahill and Alan Verhey. Yes, he’s a mentor. It surprised me and it surprised my wife, Liz, when we were doing the index to The Birth of Bioethics how many times Jim’s quoted in this book because he’s not a bioethicist, you know. And he doesn’t want to be thought of that way but at many, many critical points he has contributed something that’s been pivotal in the way in which people thought about an issue.

After Yale, looking at your CV, your first formal teaching position in bioethics was in 1972 at UCSF. What swung you into bioethics?

Swazey: Well, that’s a kind of a weird story. I tell it in The Birth of Bioethics but I enjoy telling it. When I finished my dissertation at Yale I was turning it in at the Hall of Graduate Studies and I met a friend of mine on the street, right in front of Mory’s. All the time I was at Yale I used to go up to help in a church in Guilford and this fellow, Pat McKegney, and his family were members of that church. He was the chief of the psychiatric liaison service at Yale New Haven Hospital. So I had gotten to know the McKegney’s pretty well and I used to go sailing a lot with them out of Guilford. I told Pat that I had finished my dissertation almost a month before I had expected to, and he said, “What are you going to do during the month?” I said, “I don’t know, I’ll go sailing as much as I can, I guess.” He said, “Why don’t you come down to the hospital. You’re writing all this stuff about
ethics, but you probably don’t know what an ethical problem really looks like, Al, until you’ve seen ours!” So I said okay. I actually delayed my return to California for another month and spent two months with Dr. McKegney, following him around on the psych-liaison consultation at Yale New Haven. That was my first contact with any of these issues in any realistic context. I was able to actually see in reality how complex the issues were that he was dealing with. He had a sense that most everything he was dealing with was an ethical problem. He hadn’t had any formal training in ethics. So I had that experience and then I went back to San Francisco. It had been fascinating but I didn’t think there would be much more to it than that. I started teaching; in those days you didn’t have to apply for a teaching job as a Jesuit, you were just assigned to teach in a Jesuit school. So I was assigned to teach the required ethics course, at the University of San Francisco. Within the first year or so that I was there I met the chairman of the department of surgery at UCSF, whose name was J. Engleburt Dunfy. Great name, Harvard man; he’d been at Harvard for many years and finally came out to be chairman at UCSF. He casually asked me what I did. I said I taught ethics at USF. He said, “That’s excellent. We need somebody who knows some ethics.” He was chairman of a committee to review the brain death criteria, and said, “Do you want to come to our committee meetings?” So I said, “Yes, that sounds interesting.” So for probably five or six months I went to this brain death committee over at UCSF and got interested in a problem that I had never really
known anything about. McKegney, by the way, at Yale was very interested in the
dialysis-suicide problem, and that was in 1967. By that time there was enough
data out there....

Swazey: I’m sure that must’ve come up on the psychiatric liaison service.

Jonsen: Yes. Yale had their dialysis service in place by that time and it was a troubling
question. *The Birth of Bioethics* cites a couple of McKegney’s articles on
dialysis-suicide. I encountered that problem through Pat’s showing me that issue
and then there was the brain death problem in San Francisco. Then something
really weird happened to me. I’d been teaching at USF for two years, I was an
assistant professor. I got a call from the Jesuit superior provincial, who said,
“You have been appointed president of the University of San Francisco.” I
couldn’t believe my ears!!

Swazey: Must be another Al Jonsen!

Jonsen: Yes! This is insane! I said, “I have no experience as an administrator, I have no
desire to be an administrator. In addition, this place is a mess!” He said, “We
have confidence in you.” The old “learn on the job.” It was traditional in those
days for Jesuits to do as they were told, so I was ordered to do it. And so in 1969
I started to be a college president. It was a very revolutionary time; those were the years of travail. I thought I did a pretty good job, but I thought it was stupidity at the time. I was 38 years old. I think I was the youngest college president in the country at that time. Pure fluke! I did that job for three years and then another funny thing happened. I felt I was doing a pretty good job but some people came to me from the Graduate Theological Union in Berkeley. Do you know anything about that?

Swazey: Not very much.

Jonsen: A group of seminaries, both Catholic and Protestant, that were all physically located in Berkeley, right by the university, had formed a union. It provided training for the ministry and was going to be done under a single umbrella administratively and so forth. So it was a very creative and innovative thing at a time when there was a lot of hope that the ecumenical movement was going to really change the face of Christianity. The chairman of the board of that place came over to see me at USF and said, “Would you be interested in standing for the presidency of the Graduate Theological Union?” The founding president was about to retire. I reflected on it and I thought, “that’s a very interesting.... It’s an extraordinarily innovative and very promising sort of program.” It would take me back, really, into the world of theology which I wanted to pursue. It would get me
out of USF in a gracious way which I was feeling was a dead end. UCSF was a very small-minded school. So I said yes, and they had their search and so forth, and then finally they offered me the presidency. And when they made the offer three of the schools, among the seven at the Graduate Theological Union, informed the board that they would leave the Union if I became president. They said it had nothing to do with me. It had to do with the process that the board had used, there was not full and adequate consultation. Ironically, one of the schools was the Jesuit School. So I found myself in a funny situation. I had resigned from the presidency of USF and now I was faced with not accepting this Graduate Theological Union offer. I realized fairly quickly that to go into an institution that's a union of seven schools against the feeling of some of those schools would be a stupid way to start.

Swazey: A no-brainer!

Jonsen: A no-brainer! So I declined. And I was out of both jobs. It was in the papers in San Francisco, “Jonsen Resigns From USF.” The next day, “Jonsen Offered Graduate Theological Union”, “Jonsen Turns Down Graduate Theological Union.” After all that was in the papers, Dr. Phil Lee, who was the chancellor of the medical school at UCSF, called me up and said, “I see you’re out of a job.” I said, “I am, Phil.” He said, “I’m resigning as chancellor at the end of this year and
I’m going to head a health policy program that we were able to get funded by the Robert Wood Johnson Foundation.” I guess it was one of the first, if not the first, health policy programs in the United States. He said, “We’ve got a lot of money and we’d like to have you come over and join us for a year because we think that the ethical dimensions of health policy deserve attention, and we’d like you to be part of this.” I’d already become familiar with UCSF through the brain death committee. So I said, “What an interesting offer. I won’t cost you any money at all because I can’t take a salary.” So they gave a donation to the order, something like $10,000, and I went over there for the year and got appointed visiting professor at the medical school. At the end of that year the Dean, Dr. Julius Krevans said that he was interested in having me stay on. He said, “We’ve got a state-funded position that we think we can manipulate in some ways.” Those were the pre-search days, you didn’t have to worry about a big national search. So they offered me that job and I took it. I asked my Jesuit superiors if I could do it, and they said yes. In the spirit of Pope John XXIII’s open policies in the church, I guess.

So I started at UCSF and I didn’t know what I was going to do; there wasn’t any bioethics to teach in any specific way. This was 1972, I knew about the Hastings Center and I knew about the Kennedy Institute. I knew about Kennedy because when I was president at USF I had been a member and chairman of the Board of Directors at Georgetown. It was typical in those days that Jesuit
universities would have a couple of Jesuits on their boards, usually presidents of
other places. When I was on the Board at Georgetown, Dr. André Hellegers was
putting the Kennedy Center together. I was actually on the Board that voted its
approval, so I knew a lot about that organization. I sought some help there and I
had also gotten to know Dan Callahan. Dan and I are not sure where we met each
other first. I remember vividly talking to him on a street corner in Cambridge
during one of my summer schools. He was riding his bicycle. So I spent some
time with André Hellegers and I spent some time with Dan at Hastings talking
about what a teacher of ethics in a medical school ought to be doing. Everybody
pretty much was at sea. Hastings had just started their involvement at Columbia
and they were honestly uncertain about themselves, although enthusiastic.
André’s program was just fledgling and still very much focused on some typical
Catholic issues, population ethics, abortion. But he had hired Warren Reich and
LeRoy Walters, who also was a Yale-Gustafson student. At the same time the
Society for Health and Human Values had come into being. So there were some
people out there who were beginning to talk about possibilities of teaching,
though it wasn’t clear what was going to be taught, by any means; humanistic,
humane studies…. The word “bioethics” was actually in my title at UCSF.
During that first year and the second year I was there, I took a lot of the medical
school courses; I audited them. I did a dissection and taught myself a little bit
about it, so I got the language of medicine in my head and saw some of the issues.
That was a very wise thing to do. I remember when I was at BU and we would get letters from people just getting their PhD in philosophy saying they wanted to go into bioethics or medical ethics and did they need to know anything about medicine? If you have to ask that question I don’t even want to look at your resume!

Stay away! It was a very useful thing for me. I got acquainted with faculty who were interested in why I was there. So I got a lot of nice connections at the faculty level, but perhaps the most important connection came in neonatology where the neonatologist, Bill Tooley, an extremely prominent person in the field, asked me to come and participate in the rounds in the nursery. He had seen the “Johns Hopkins Baby” film and wanted me to talk to his course in reproductive medicine after he showed that film. Bill and I became very good friends and I became a regular participant in the nursery. That experience gave me a clinical appreciation of the issues. I learned enough about the science, and medicine, and taking care of the newborn, that I felt very comfortable discussing the issues that came up. It gave me a kind of clinical respectability; people knew I was willing to be there on the service. And then I did the same thing fairly rapidly in the adult intensive care unit, once again fostered by the chief of that service who thought it was an interesting thing to have a discussion of ethics. So I didn’t go just as a consultant, I really hung around a lot! I was learning an enormous amount. So
those first several years, I think, established me in a way that I would never
enjoyed if I had come in just as somebody giving classes to the medical students.
I became very much a part of the life of that institution in the years I was there,
from 1972 to 1987. I was on the IRB from the beginning, the Chancellor asked
me to chair the first ethics committee, when they put it together around 1980. I
was elected to the Faculty Council. I was on all sorts of committees. I had a big
advantage too, in that I was fairly well-known in San Francisco when I came
there. There was name recognition, people knew who I was and that was great.

Swazey: The unemployed guy!

Jonsen: Yea, the unemployed guy! But I’d been in the papers a lot and so forth, like
college presidents in a small town and USF was very much an establishment
school in San Francisco in those days. It had a great basketball team, in its day.
Bill Russell was a USF student. I had, at one point in my career as president,
abolished the football team which gave me a lot of publicity.

Swazey: Probably negative.

Jonsen: Yes, it was! People were saying they would never give this school a penny again,
and they had never given a penny before! So that was an advantage when I
arrived at UCSF, which generally would be a forbidding place for a stranger like me to come in to.

Swazey: Did you wear a collar?

Jonsen: No, I didn’t. I got permission not to. Those were the days when clerical mufti was becoming more common but I clearly felt that I had to distance myself from clerical identity. I remained an active Catholic priest until 1976.

Swazey: Were people at UCSF aware that you were a Jesuit?

Jonsen: Yes, most were. It generally didn’t seem to be particularly bothersome to anybody. It had to be fairly clear that I wasn’t there as a chaplain because once in a while Catholics would come to me and say, “Would you perform my wedding?” Or somebody would come in and inquire about the possibility of divorce and that kind of thing. I just said, “wrong office. There is a Catholic chaplain here, go see Father Burns and he can help you.” But I gradually became emotionally distanced from the church. There was a fairly strong reason why that happened and that is, as I’ve told you, that my career was intended to be one in the field of moral theology. During the years that I was at USF there were very strong papal pronouncements against contraception, and I felt that I couldn’t be a teacher of
Catholic moral theology, given that position. There was a time when there was
enough flexibility in the Catholic position that a clever moral theologian could
wiggle around, but the papal statements in 1967 or 1968, whatever it was, really
closed those doors. And to be a teacher of Catholic moral theology with that kind
of restriction, I thought was unconscionable. There was some relief when I
moved to the presidency because I wouldn’t have to teach. Also Catholic position
on abortion was unacceptable to me. I thought it was untrue to its own historical
roots. Since two main issues were ones that I didn’t feel very comfortable with,
going over to UCSF was great. I didn’t have to worry about that at all. I could
begin to explore the possibility of teaching ethics, in a secular setting and to
people who were not philosophy students. That was the challenge that I
immediately recognized: if you’re going to teach medical ethics you have to create
something new and you have to attempt to make it, in some way, related to what
ethics has been traditionally thought to be in our culture. It must respect moral
philosophy and moral theology, and public morality, those kinds of general public
beliefs that float around, but you can’t make it a metaethics course. When I
started at UCSF, there were a few textbooks around. There was Joe Fletcher’s
book which I tried to use in the first year for the medical students’ elective class.
It flopped completely because by that time most of the issues that he was
struggling with such as abortion, contraception and artificial insemination were
taken for granted. I found that The Principles of Bioethics didn’t work because it
was much too philosophical. Gorovitz’s book didn’t work because they couldn’t see the relationship between medicine and reading two pages of Emmanuel Kant. So we had to create medical ethics from the beginning as a new thing.

Swazey: When you’re talking about this period in your work you’ve been using a term “medical ethics.” And when you said “bioethics” you’ve almost corrected yourself and said “medical ethics.” What distinction are you making?

Jonsen: Well, I guess I don’t make a terribly formal distinction between the two, but I think there is an historical distinction. The historical distinction is the shift that begins to take place in the late fifties and early sixties when questions of the appropriate use of technology and science begin to arise. As distinguished from what I call in the book “the long tradition” which was primarily doctors’ ethics. The behavior of doctors toward their patients rather than an exploration of the justification for decisions. So I’m willing to call the latter bioethics and basically say the tradition prior to the 1950’s is medical ethics. But in the context that I’m talking about at UCSF, I think we used medical ethics because it was still current language and it seemed appropriate to the setting in which we were.

Swazey: Actually I called my seminars at BU Medical School medical ethics too. That was in the early 1970’s and I’m not sure that bioethics would have meant anything.
Also the word “bioethics” in San Francisco in the 1960's and 1970's was immediately associated with all sorts of kooky stuff. You know, macrobiotics and biofeedback and all that stuff. So although I had the title, Professor of Bioethics, that was because André Hellegers thought I should. The dean asked me whether I wanted to be called Professor of Medical Ethics? I went and also talked to Dr. Otto Guttentag and Dr. Chauncey Leake two famous names in medical ethics who were at UCSF. I talked to them about what I ought to be called. Both of them were wonderful, very gracious. They didn’t think that I should be called Professor of Medical Ethics because they thought that was physician’s language. It should be a physician who did medical ethics. It should be exclusively with physician behavior. Both of them said there were all these new questions and a new term was advisable. It was André, actually, who thought it was time to use the term “bioethics” in that setting. Those two old timers, Guttentag and Leake were really marvelous.

They did some really important things.

Guttentag was very important in the human experimentation issues.

Have you ever read *The History of the Society for Health and Human Values*?
Acadia Institute Projection of Bioethics in American Society
Al Jonsen
page 36

Jonsen: Yes.

Swazey: To me it's fascinating looking at the work they were doing in the very early fifties. The United Ministries pushing for medical education, task forces on human experimentation long before it got to be a highly visible set of issues.

Jonsen: They really did some remarkable things.

Swazey: You certainly are a leading representative of bioethics going to Washington and bioethics entering into the policy arena. Can you talk a little bit about what got you into the Washington orbit? I guess that started in 1970 when you were appointed to the Artificial Heart Assessment Panel, and how that came about.

Jonsen: Yes, that was my first involvement. I was still president at USF when that occurred. I don’t know, to this day, how my name surfaced at the National Heart, Lung and Blood Institute. I have two possible explanations. One was that André Hellegers may have been the source of that nomination because, he knew Dr. Ted Cooper, who was the Director of the Institute. Another possibility is that Dan Callahan suggested me. When I asked Dan; he said he can’t remember whether he did or didn’t. That appointment came out of the blue. It was just at the time that I was transitioning out of USF, but I was still president then. So that was the
beginning. It was a very interesting experience because I think it was the first
time the government had ever attempted anything quite like that. We were
inventing something out of whole cloth. The process was limited by the fact that
the panel was given a very restricted charge. I learned then that when you start
talking about ethics and government things, you talk about ethics the way they
want you to talk about ethics. There wasn’t much that really surfaced as an ethical
problem with the exception of the problem that had been originated by the dialysis
issue; that is the selection question. I struggled to make everything into ethics. It
was the selection issue that basically got the treatment. Well, there were actually
two issues; there also was the experimentation question of how you move from
animals to humans and what steps you take. Jay Katz however was on the
committee, which was a great thing for me too because that’s where I became a
good friend of Jay’s. He became the experimentation expert. I tell in The Birth of
Bioethics a little story that I think is very illustrative of the problem of bioethics at
that time. I was acquainted with the selection issue because of the dialysis
experience and I had read all that literature. We went around debating about
whether there ought to be a lottery or selection criteria, and so forth. Clark
Haviñghurst was on the committee. He is a lawyer at Duke, a very, bright guy,
very well-read. He read Rawls’ Theory of Justice, which I hadn’t read, and he
came to a meeting with a copy and said to me, “Jonsen, have you read this book?”
I was ashamed because I hadn’t read a book that was in my field. He said, “We
ought to underpin our whole report by using this theory that this guy espouses in this book.” So I went home and read the damn thing.

Swazey: It’s a long night’s read!

Jonsen: It sure is! I had a very hard time figuring out how it might be applicable to what we were dealing with. It seemed to me an absolutely gorgeous exposition of ethical theory. I was very much impressed with it, but I hadn’t a clue as to how to use it. I think that’s a very revealing story about bioethics: if you go in with ethical theory even in its most impressive forms, drawing that theory down to application, to policy or to practice, is an extraordinarily difficult translation. I didn’t know how to do that and I still don’t know how to do it. Norman Daniels has been much more successful in using Rawls’ theory in his general treatment of allocation of resources. But I think that it’s probably a generalization that ethical theory has never really been very important in bioethics.

Swazey: I want to come back to that point too. Were you on the Artificial Heart Assessment Panel as a philosopher or a theologian? Did they make a distinction?

Jonsen: As an Ethicist. By the time that Panel came to an end I was actually at UCSF, but I think I’m still an “SJ” on the panel list; it says “Reverend”.
Swazey: Was it that experience that then led you into the National Commission?

Jonsen: Yes, I guess it was. There were relatively few of us who were card-carrying ethicists! The National Commission came about in a somewhat different way. Let’s see, we’re talking now in 1973, the Commission actually had its first meetings in 1974. By that time I had been in Washington as a Fellow at the National Library of Medicine for a semester. I did that after a couple of semesters at UCSF. I thought it would be a good thing to do some concentrated study, so I went to the National Library of Medicine, which gave me an opportunity to spend more time at the fledgling Kennedy Institute. And I also went up to Hastings every couple of weeks, at Dan’s invitation, to talk about bioethics and policy. We had a little seminar. I took the train up to Hastings. So that was an opportunity to get to know the Hastings people, Callahan and Veatch, in particular. I think that what happened in the appointment process was this: I know, as a moral certainty, that André Hellegers was a very significant figure in having that National Commission put together, having the members appointed. You’ll find an amusing story in the book about the initial steps which I won’t go into here, but André was in it right from the beginning with the Shivers and then with Ted Kennedy. I think André did pick me for that nomination because he wanted to avoid charges of nepotism with The Kennedy Institute; the first thought probably was somebody from the Kennedy Institute, either LeRoy Walters, or Warren Reich, or Dick
McCormick if he was there. I think Dick McCormick was there at that time, but André said, “No, don’t have any Kennedy Institute people because we don’t want to have nepotism.” The consequence of that was...don’t take anybody from Hastings either. So he indirectly vetoed Hastings people, and I showed up as the neutral party. I was a pretty good choice for the Commission because I had a lot of the characteristics for a government appointment. I was a Catholic theologian but I was not teaching in a Catholic institution, I was in a state institution. That was good. So I was kind of the Catholic, but I wasn’t the Catholic. I’d been educated in ethics, both inside and outside of Catholicism. I was a Yale graduate and so forth, and that was good because you were kind of a safe Catholic, not an ideological Catholic. I used to joke because I was a Catholic but I had a Jewish grandfather.

Swazey: That’s fascinating, because I’ve often wondered as you look at those Commissions, where was Hastings and where was Kennedy?

Jonsen: Hastings didn’t get in at all. Kennedy got in indirectly because Karen Lebacqz had been a Kennedy Fellow at Harvard, but that was pretty remote. Karen was one of the few early people in the field; I guess she was there the first year the Kennedy’s founded the Harvard Fellowships.
And I gathered that was pretty much, “We have money for you, do your thing.” It
was certainly not a bioethics program.

Yes, there was very little structure to it.

That’s when George Annas got his MPH, as a Kennedy Fellow.

Did he? I didn’t know he was a Kennedy Fellow.

Yes, he was in that first group and he said there was no “ethics” or “bioethics”.
So he figured it was a good chance to get his MPH.

It was Bill Curran and Arthur Dyck and I guess Stan Reiser was part of that too, as
the kind of faculty group. So Hastings was not a part of that Commission,
indirectly or directly. But Bob Veatch had a big advisory role in the formation of
that Commission stemming from his advisory role to the Kennedy hearings. So
Hastings was certainly known to the Kennedy group, to the Senator’s office,
because at those hearings Dan Callahan testified several times, Will Gaylin
testified, and Bob Veatch was an advisor to the Kennedy staff. So Hastings was
certainly known but they didn’t have a direct input into the Commission. It may
be that Dan was reluctant to get too close to government stuff.
There was a lot of debate, I remember because I was in the early group of Fellows, as to whether Hastings should get involved in policy, whether they should go to Washington. There was a lot of unease about it, particularly I think about connections with the Kennedys.

I think that would be a good question to explore with Dan because I had that feeling too. If they did come to him he might have been reluctant to do it because he is very sensitive to getting captured by anything; that’s why he didn’t want to get involved with the universities in the beginning. So there were two ethicists on that Commission, Karen and me, but both of us were theological which is an interesting thing too.

What were your expectations, if you can go back that far in time, about what the Commission was going to be able to accomplish? What did you see its role as?

Well, that’s a good question. It goes back to what I said about the artificial heart: when you take on these tasks you are given a mandate. So, in a sense, you never ask, “What are we going to accomplish?” Because we are going to accomplish what we’re told to accomplish. There is a very complete list and it’s always in front of you, and the executive director is kind of ticking off each thing. So there’s almost no time to be really reflective about what this Commission really
ought to be doing because you are told what you ought to do. Secondly, it was
again one of these learning experiences. What does ethics have to do with these
things? How does it fit in? We knew the history of things, we knew the
statements. At least I had read all the literature and the Daedalus essays and The
American Academy of Arts and Sciences proceedings and so forth, which were
really influential in my thinking, particularly Jonas’ essay.

Swazey: I hope people are still reading that, younger people.

Jonsen: I hope so too. It’s a classic. Of course, we also had Jay Katz’ big book, which
was given to the Commission at the very beginning. So the question was, what
are we to accomplish in a broader sense than just going through the mandates? I
guess I probably thought then what I think now, that it’s this task of giving shape
to the discourse that is the principal role that an ethicist plays in these kinds of
discussions. I thought Karen Lebacqz did that very well. I admired Karen’s
ability to give shape to a discussion, and I think I do that fairly well too because
ethics discussions tend to go round and round and round. To kind of get it off the
circle and moving in a certain direction and doing that, not the way a good
chairman does with a discussion, but saying, “When we’re talking ethics, here’s
the significant thing that we’ve got to get to.” That oversimplifies it, but you can
talk about the conditions under which people are asked to volunteer when they are
patients. You can talk about that at great length, but you can focus on ethics if you say in the midst of what is largely a phenomenological or sociological description, "What does autonomy mean in this kind of a setting?" There is an essay that John Fletcher wrote very early on. Actually it was his dissertation at Union Theological. He went to NIH and studied informed consent in the context of seeing people actually being asked, and says, "What does autonomy mean here?" And so I think that the ethicist comes in with ideas like autonomy in their head and listens to a discussion that can be very empirical and sociological and says, "Well, if we're going to make an ethics discussion out of this, let's see what the features of this concept of autonomy are that make sense in this sort of a setting, or do they make sense at all?" I think that Karen and I did that a lot in the Commission. For The Birth of Bioethics I did go back and read through much of the transcripts. It astonished me how inarticulate people are when you think you're being articulate!

Oh yes. I've gone back and looked at the Research Integrity Commission transcripts and said, "Oh, Lord!"

It's amazing, isn't it? But I think that really was what was done and I think that the height of that was in the formation of The Belmont Report.
Talk to me a little bit about the creation of The Belmont Report.

Again, there was a mandate in the Congressional legislation for the Commission to...what was the word? Not to develop the ethical principles governing research....

To define them or articulate them or something.

I forget the exact language. So the first thing the Commission did was to commission some philosophers and theologians to write about ethical principles and what it means to develop them, or define them, or whatever it is. It's in the book there. So we had Alasdair MacIntyre, and Jim Childress, and LeRoy Walters, and Tris Engelhardt, and Kurt Baier write essays on the concept of ethical principles. In itself that is a very interesting exercise for several reasons. First, one of the important landmarks in the development of bioethics was the commissioning of these and other papers that the Commission got philosophers to write, because it began to draw them into a field that they had not been familiar with. It's also interesting to think of a Commission sitting down and saying to a bunch of philosophers, “Tell us what an ethical principle is.” We got very different views from all of those people because there wasn’t any consensus of any sort. There wasn’t any ethics out there, in the way in which there’s a
mathematics out there, that we could just latch onto, but we got a number of
different viewpoints about ethical principles; some of them quite original. There's
not a lot of discussion of principles in ethics up to that point, believe it or not. So
we read those papers and then the plan was made at a certain period, I don’t
remember how long it was, to have a retreat to discuss the ethical principles. We
had these papers in hand, a good number of them, from our consultants. We had
some general discussions about what we thought ought to go into this statement of
principles. Naturally we knew that there were the codes that had already been
created at Helsinki and Nuremberg. We felt that we ought to go beyond that and
we ought to try to create a document which did give some philosophical
grounding to the kinds of things that were said in the codes. And of course, we
also were aware that the big cases, as it were, that were around at the time, like
Tuskegee and Willowbrook, set a certain direction in which our thinking was
likely to go. So we had the meeting at Belmont House, which is a Smithsonian
Institution Retreat. We broke up into some subgroups together with our
consultants to talk about the various aspects of the document because, in
accordance with what was in the legislation, there was discussion of principles
which were to deal with informed consent and risk-benefit. Everybody came back
and gave a report. Karen Lebacqz was the chairperson for the committee on
principles, and that committee came back with, I think, seven or eight principles.
You weren’t on that committee?

No, I think I was on risk-benefit. There was quite a vigorous discussion about how many principles there ought to be. And as I say in the book, it was actually Joe Brady, a behavioral psychologist from John Hopkins who suggested three principles, simply because he said that seven wasn’t very aesthetic and he thought there were too many and we ought to have a parsimony of principles. I agreed with him that we ought to be working toward a much more concise statement. We thought several of the principles that were on the list from the committee could be reduced to one. So that was the substance of the discussion about how many principles, and that was the point at which autonomy or respect for persons, beneficence and nonmaleficence and justice were sorted out. That was very much in conformity with two papers from two of the consultants: Tris Engelhardt’s paper and a paper that Tom Beauchamp had contributed on justice. Those papers had a lot of effect on the thinking of the commissioners. Then there’s a fairly long period of time after Belmont when there were drafts going back and forth and back and forth. There were not substantive discussions at the meetings but a lot of drafting and redrafting that was submitted to the Commission. By the way, it is really the case that the Commission was commissioner-driven, as I think that Brad Gray has subsequently said. That is, the commissioners did most of the writing; we wrote it in pieces and we shared it and argued about it rather than having staff
do the substantial drafting, which happened in the President’s Commission. Then
there was a meeting of which there is no record, for reasons I have no way of
knowing. There was a meeting at my house in San Francisco. It was Michael
Yesley, Stephen Toulmin, and Karen Lebacqz, and Joe Brady, and myself, I think
that was the group. We were charged with doing a final draft, and we spent two
days at my place and worked our way through all the text that we had and argued
out the arguments that we wanted to have in this document, had a general
consensus that it ought to be very brief, and so forth. I typed it. I sat there and
typed language as people were talking. This was in a room that was on the roof of
our apartment, which was my study, with a wonderful view of the city. We
commonly called that room the Belvedere so my claim is that it’s “The Belvedere
Report”, you know. But we really substantially shaped it into the form that it has
today. It went back to the Commission, had some more changes that were
relatively minor, then it was given to Tom Beauchamp to redact it. He was, by
that time, the full-time consultant in the position that Stephen Toulmin had at the
Commission’s beginning. Tom gives himself, I think, a much larger role in the
creation of that report than I remember him having. I don’t think he was really a
participant until the very end when he was to do the final wording and shaping of
it. But I don’t think he was a substantial contributor although his paper for the
Commission on justice contributed some ideas. Tom has consistently made it
appear that The Belmont Report was something that came out of his mind
together with Jim Childress because they were contemporaneously working on the book with those principles. But I don’t think that’s true. “Respect for persons,” the first principle, as I remember it, got its wording largely because of my favoring that language in a book that I had recently read. A relatively recent book on Kant’s philosophy called *Respect for Persons* by Robin Downey. I liked the language and Karen liked that language too. I think Tris Engelhardt used that in his essay. So we chose “respect for persons” rather than “autonomy.”

The key feature of that report, in my mind, was that it linked each principle with a practice, so where there is discussion of “respect for persons” in kind of a broad, moralist, philosophical way, then it says, “informed consent is the practice that manifests respect for persons. Beneficence and nonmaleficence are the principles which lie behind risk-benefit assessment. And justice is the set of principles that lie behind the allocation of benefits in research.” There were people like Don Seldin on the Commission who wanted this to be a genuine philosophical treatise. I didn’t think that was the right way to go. We prevailed on that; most of the commissioners felt that it ought to be brief, only modestly philosophical. And that’s been a weakness, not in the document because I think the document has served its purposes very well, but it’s been a general weakness in reference to that document as setting out principles because the principles are not very well set out. There are rough definitions given and some very modest support for the importance of those principles in the document itself. That’s
where Beauchamp and Childress actually improved the situation by taking
principles that are at least analogous ones because they wanted to break out four.
Under “respect for persons” we also put protection of those deemed mentally
incompetent. They wanted to break that out and put it in nonmaleficence, so they
did some shifting around. But they began to do what the document doesn’t do,
that is to put those principles into a context of philosophical argumentation and, to
some extent, into a historical context of philosophical thought. Engelhardt, in his
original paper for the Commission, had really taken the Kantian view in “Respect
for Persons” and based his thinking on that. By the time you get to Beauchamp
and Childress they’ve said, “There are Kantian roots to this and then there are
Millsian roots to this.” And of course those two roots are growing in very
different gardens. There’s been a mix up ever since about what’s being done with
that principle at the theoretical level. At the practical level it doesn’t make that
much difference. So Belmont really came out, I think, as a document that was
responsive to the mandate from the Congress. It was intended to be brief, and it
was intended to link some concepts and theoretical points to some practical points
that could be turned into behavior on the part of those responsible for research. I
was very happy with it, although as I go back and look at it now I find it rather
naive.

Swazey: Well, I think that’s because there’s been so much water under the dam and it’s
easy to forget that it was in many ways a path-breaking statement when it came
out. And it certainly has to have been the first time that Congress asked anybody
to define ethical principles in any legislative mandate. It’s pretty bizarre. I’m not
sure it’s happened since.

Jonsen: I say that in the book; it’s amazing. I think that Charlie McCarthy was probably
the one who actually wrote that legislative language.

Swazey: I’ll have to ask Charlie.

Jonsen: Ask him that. But you’re quite right, it’s a first on stating ethical principles.
And of course, everybody recognizes that that little document had an enormous
effect on the creation of the discipline because it gave a set of ideas that were
fairly succinct around which people could begin to think. This is a more subtle
point, but maybe one might say that the fact that we put “respect for persons” first
and “beneficence” second is a manifestation of this general shift between medical
ethics and bioethics that moves from a paternalistic beneficence point of view to
an autonomy patients’ rights point of view. Although there is another way to
interpret that too, and that is that it does reflect the historical circumstances of
Nuremberg where the consent of the subject is the first principle. Also the
document clearly reflects the Jonas view on research; I mean, one can find it there
if one knows what Jonas said.

Swazey: Do students still read Jonas's essay in the *Daedalus* book? Is that something you assign?

Jonsen: No. We will if we get our NIH grant to create a course on research ethics. They certainly will read it because for me that's the heart and soul of research ethics. I suppose that we would go at it differently if we were sitting down again to reflect on this. We'd go at it with the current problematic in mind. We were going at it with the problematics of Willowbrook, and Tuskegee, and Auschwitz in mind and with the history of abuses. If we had known about the radiation research that would've even pushed it further but we didn't know that...didn't know a thing about it.

Swazey: That's another fascinating chapter. Sort of like Tuskegee...years of silence.

Jonsen: We should've known about it! We should've been informed by DOD, but we never were. And so I think we would probably be much more subtle about the meaning of research than we were then. In terms of the meaning of research, we depended a lot on Bob Levine's essays for the Commission, which painfully worked out the idea of what research is in distinction from practice. We were
convinced that the primary feature of research was the design of a protocol which
essentially revolved around a null hypothesis. And we were clearly living in an
era where scientific research was insulated from a whole lot of other influences.
That is, scientific research was done by scientists within a relatively quiet world.
The NIH had made it more public by putting so much money in it. But as I say in
the book, medicine began to call attention into itself by vaunting all of its
miracles. So the climate of research in 1971 was still a fairly quiet one, with these
occasional eruptions of scandal. But now it’s a public enterprise, and that
probably in large part happened because of the AIDS issue. AIDS certainly had a
big influence on it. But the idea that somebody would know what research was,
and how it was carried out and so forth, beyond that little quiet world was
unthinkable. And now that’s not the case. What we see now is that every
development from initial laboratory studies on, particularly in areas that are
matters of public attention, seem to be known about. They begin to acquire
promise at the very earliest stages.

Swazey: A therapeutic misconception.

Jonsen: Yes, very much so! That gets out and it’s much more widely known to larger
communities than it was in that quiet little scientific world of the early 1970’s. So
now it is much more difficult to distinguish research from a whole lot of other
ideas that get picked up, it’s scientific enhancement or saving of life...all of that.
You never thought about research saving life until somebody was trying to get a bill passed in Congress for the NIH for the disease of the month. But the research itself wasn’t life saving. Now we think of the very earliest evidences that are coming out of a study as being “life saving.” So I think we’d go at it very differently. My guess is that the idea of justice would go way up to the front and maybe even trump autonomy, because I think what the contention here is, to what extent do these new things move out into practice in a world which is already constrained in its health care resources? Can we afford as a nation to produce all of this new stuff at a time when there is so much difficulty in access to the common, ordinary, already-out-there stuff? It’s in that context that I think that the autonomy question has got to be viewed. Autonomy now becomes settled within this larger question of allocation of resources. The justice part of Belmont is a pretty tiny little conception of the fact that you shouldn’t do all your research on poor people. That’s about all it says. But I think a revised, revisited Belmont would have a much larger place for justice, which has a whole set of interesting ramifications.

Swazey: In that context, have rights now become my right to have access to research, whatever drugs, procedures?

Jonsen: No, I don’t think so. If you start with justice you take a tack which American
philosophers were not taking back in those days. We were thinking about rights
as an independent concept in ethics. Basically it was my right against your right.
So we’re two people who each have a claim to this cup of coffee: I have a right to
it because I bought it, and you have a right to it because you need coffee to stay
awake. And we argue about whether your need trumps mine. That was a weird
view of rights but it prevailed for a long time. I think today, at least, philosophers
are much smarter about rights. That is, that rights are essentially the points within
a network of social relationships. And they establish places within that
relationship which may have certain kinds of absoluteness to them if you make
arguments strong enough. But it’s not just me versus you. It now says my right,
relative to my cup of coffee, has a lot to do with the social institution within
which people can buy coffee and the social institution of giving, and lending, and
borrowing. So I think that a discussion of research rights, rights to be a
participant in research in the old view of “I need it, therefore I must be allowed
in,” would be viewed very differently within a context of justice. The best
example that I know from another experience has to do with bone marrow
transplant for breast cancer after high dose chemotherapy. A very investigational
procedure, five years ago...a very investigational procedure. But as soon as it gets
reported people are demanding its use. This is not just a research question but an
allocation question because it was a question of whether the insurance company
was going to pay for it or not, but basically it’s the same issue. People came in
saying, "I don’t care whether you can tell me if this is efficacious or not with your
data, that’s not relevant to me. This is my last chance, therefore, I have a right to
it." Well, taken alone in itself you say, "As a matter of compassion one might
respond to that." But if you take the question of justice in the larger view of the
availability of resources within a health plan, "Can we afford to allow people, in
principle, access to procedures whose validity we know nothing about, or know
little about?" And what that needed was, and in principle is possible to give, a
good strong theory of justice in the managed care, or the insurance world, or so
forth and so on. If the insurance world weren’t so distorted by greed and
maleficence.

Swazey: Talk about ethics!

Yes. That’s why I think that one of the things that would happen in a revised
debate over Belmont, if autonomy or respect for persons kept its primacy of place,
is that it would be very easy to build into that a right of access to research.

Swazey: But of course your job in the early 1970’s when you were drafting Belmont was to
focus on protecting human subjects, and that’s very different from saying, “Our
task is to think through the ethical principles involved in social justice, and is
there a right to access?” That probably never even crossed your consciousness,
given the cases you were dealing with.

Jonsen: It never did. The only place that it ever came up was in this little minor discussion of justice where we said, “Shouldn’t people be able to get compensation for injuries...” Oh, you know where it came up? That issue came up in prison research. The guys in jail saying, “You can’t deprive us of the right to be research subjects.”

Swazey: That’s right, I remember that.

Jonsen: “That wasn’t taken away from us when we were put in jail like the right to vote was. Why shouldn’t we be allowed to be research subjects? We want it.”

Swazey: “We want to give our kidneys.”

Jonsen: Yeah, sure. And so it did come up in that kind of odd, side context of a right to be a participant. We were almost persuaded by that, you know. The prisoners report, which came to no good in the long run, essentially affirmed that, and said that the problem with research in prisons is not that prisoners can participate in research but there is so much coercion, and so much inducement from researchers but that there is so much corruption in the prisons. If you clean up the prison situation
there would be nothing wrong with prison research. Joe Califano, who was the Secretary of DHEW at the time said, “It’s not my business to reform prisons.” So they just stopped research in federal prisons.

Swazey: But as you said, it’s a very compelling argument on the prisoners’ part.

Jonsen: Yes. That was a very striking experience, the prison visits that we did. I’d never had any experience with that world before. I guess we visited six or seven prisons with big research projects. What was obvious, first of all, was that the prisoners wanted to participate in research. Secondly, that it was not particularly risky research anyway. It was fairly innocuous stuff for the most part, but the really impressive thing was that prison research essentially had been captured by the prisoners...the inmates. Essentially every research enterprise, even run at a very high level of efficiency by Merck, or by whoever was in there running it, those guys, the inmates, had grabbed it...had control over who got in and who got out. They passed it out as a favor. They’d keep guys out that they didn’t want. They had total control.

Swazey: Reward system.

Jonsen: Yes! Just like everything else in those places.
It will be very interesting to see what NBAC does in terms of the 20th anniversary of Belmont. Are you going to be talking with them about that?

That’s what they asked me to talk about. I haven’t talked specifically about what they want by way of the presentation. It would probably be impossible today to write so simple a document. It was as much a declaration as it was a report, you know. It’s really a declaration that research does not belong to the doctors, it doesn’t belong to the researchers. And it’s Hans Jonas’ concept that there has got to be a partnership. I think that’s what the declaration was and that was needed at the time. One other point is that I think it might also be a mistake to be too radical with any sort of revision of Belmont in the light of these new circumstances, because I think the old problems still exist and are likely to continue to exist.

I have continued over the years to collect cases that come up in the media. I almost have a sense that there was a quiescence in the 1980's. People weren’t paying as much attention. Late 1980's to the 1990's there have been a heck of a lot of cases, a lot of them around the mentally ill.

Yes, that’s a very serious issue.
That never got dealt with by Washington, for reasons you know of.

That’s right. I think that the system, the IRB system and the review system and so forth, did a lot of good but it’s become routinized. And I think a lot of the people on IRBs don’t really know much about the background of why such bodies even exist.

I think ones that do, someone like Leonard Glantz who’s on the BU IRB, is basically stifled. They don’t want him to open his mouth because he is going to raise issues. That’s a very sad commentary. Some IRBs have become a rubber stamp.

Yes, it really needs to be revitalized, the system does. Perhaps in some different way than we presently do it.

Do you think there should be a standing ethics advisory commission or board, the type of thing that Jay Katz has argued for for years?

I do. I think the Ethics Advisory Board that DHEW had should be revived and it should be given power. I think that it could be a stimulus to improve the system.

Where would you put it?
Well, I guess the same place that it used to be, under the Secretary; it was an advisory board to the Secretary.

No, I see this as largely having to do with the research enterprise as such and I think that the EAB is still in the law, it’s still in the regulations. It expired just when the President’s Commission started, so that was 1979 or 1980. There are a lot of things such a body could do, and it would have a kind of continual input into the system to keep it greased and keep it effective, much more so than just OPRR, which has very limited resources.

And is much too busy with animals....

Well, I guess that’s right!

Well, the animals have a much more vocal constituency than human subjects.

Yes!

Would you see a need for a broader based ethics/bioethics advisory body of some
sort that looks at a broader range of issues than the EAB did?

My feeling generally has been that such an entity should be an occasional rather than ongoing thing. I think if there was an ethics advisory board in place relative to the research world, and maybe with a slightly broader... In fact, Califano did give it a broader interpretation he said, “You can advise me on policy beyond research.” He wanted them to advise him on tobacco policy which was a big issue in his mind. But I think to have a free-standing commission, or one like the President’s Commission or, now NBAC, I think that ought to be occasional. I don’t have many good reasons for that except I tend to think the more organization you set up in government and let run on and on they start doing kind of silly, extraneous things after a while...like Prosecutor Starr. They go hunting around for things; they do the original mandate and then go hunting around for things. I don’t know. I’d rather see these commissions be like the royal commissions where they come into being for a special purpose, and do them and go out.

Can you do any broad brush stroke characterizations and differences between the National and the President’s Commissions, since you sat on both?

The one that I’ve already said I think was the striking difference is that the
National Commission really was a working Commission in the sense that all of us were very active participants in the writing of documents and we really, within the scope of the legislative mandate, set our agenda. Michael Yesley was very much a responder to the Commission's needs and desires. Ken Ryan really did run that Commission. Also, it had a lot of money because we really didn't have a budget, NIH had to pay our bills. So we got a lot of things done. We were able to commission a lot of material. We could have people come in from all over. The President's Commission was Alex Capron's Commission, he took over with a very firm hand and a firm sense of what he wanted to do. He had his staff in place even before the Commission was appointed. The agenda was set but with much less rigor than the previous Commission. The reason for that as you know, was that the National Commission had to make recommendations which had to be responded to in a certain period of time by the Secretary. The President's Commission didn't have that and so its reports more or less floated out. It didn't give that kind of specific directedness to the creation of the products. So Alex had a lot more to do with setting directions than existed in the previous Commission. I think that Ryan was a much more effective chair than Morris Abram was. Abram was an effective chair in the parliamentary sense, but I don't think he understood very clearly what some of the issues were and what some of the ideas were that were presented. I don't think he has any natural affinity for philosophical reasoning, which Ken rather does. He's not a philosopher but he
likes that kind of argument. And so Alex really ran that show. We wrote very little of the documents. There are some pieces of some of those documents that I think is my language, but it was essentially written by staff. So we’d get it and we’d criticize it, but when you get back a big document, once it’s in place it’s pretty much set. There’s not a lot you can do. There are a few times when the commissioners rebelled on that point. The drafting of the “Splicing Life,” I was very critical of and it did go back. Arnold Motulsky was very critical of it too, and it got a reworking. The other major rebellion of the Commission was the rebellion against the “Access to Health Care” document. I was off the Commission at the end and I didn’t participate in it, but that’s where the conservative Republican members who had been appointed to the Commission by Reagan completely rejected the draft report. The draft report was basically written by all these young liberal philosophers that Alex had gathered together. So they sent that one back for...I guess one might say, “a gutting.”

Swazey: Were you on the Commission when that whole report was being discussed?

Jonsen: Yes, in the early phases.

Swazey: Because I gather from talking with Alex and others, and this opens onto a broader question, that there was some debate within the Commission as to whether access
to health care was a bioethical topic. Should the Commission be dealing with
that? The larger theme that raises for Renée and me is our sense that those larger
social justice issues, with the exception of some people like Norm Daniels, have
been largely neglected by bioethics. First of all is that correct? Secondly, if so
why?

Jonsen: I think it is correct and I think there are a number of reasons why. One reason has
to do with the state of philosophical ethics, in which the large justice questions
were not at all central, even for the people who were interested in normative
ethics. Ethics in American philosophical writing of that time was largely personal
behavior. It was issues of norms of personal behavior, not norms for social
structure. It was Rawls that really shattered that conception and came in with a
very, very dramatic thesis about the structure of ethics and the structure of society.
In a sense it's obvious that the justice questions have been around ever since
Plato, there is not doubt about that. But in American philosophy at that time there
wasn't any interest in them at all. And so that was one reason why original
bioethics, if you look at its ethics input, tended not to think in terms of social
justice. Actually, the same thing is true in theology but in a funny way. The
theological world had for several decades been very interested in social justice,
both Protestant and Catholic. The social gospel movement within Protestantism,
the influence of Reinhold Niebuhr for example, had emphasized social justice,
and then relationship to the social movements, and the union movements and so forth. The same thing was true in the Roman Catholic world. There had been several papal encyclicals on social justice. There was a big social justice movement in the United States that was very much union associated. Remember On the Waterfront? That was Father Corrigan, I think, in New York who worked with the unions, but that was true all over the country. Interestingly enough the theologians, who were so influential in the beginning of bioethics, knew about all that. But we didn’t bring that at the beginning, we bought into this problem of individual behaviors because we were drawn by the problematic that was set up in those days of paternalism...the paternalism problem.

Swazey: Who set that up? Didn’t you set that up yourselves, in part?

Jonsen: We didn’t really set it up. We inherited it as a view of what medicine was. Certainly if you look at just the research problem, which becomes, in a sense, problem number one in temporal terms, the question of the authority of the researcher versus the autonomy of the subject set that problem up because that was the natural conception in the stories that we were living with, and in terms of the nature of research...the superiority of the researcher. I think that if one looks at some of the social commentary on medicine in the 1970's, that you and Renée know so thoroughly, they were setting that issue. Friedson told us to view
medicine that way. Illich told us that that’s what medicine was. So it’s something that the bioethicists found when they started work. If you look at the social criticism of medicine that was current in the culture before we even picked it up, some of Will Gaylin’s early remarks are very strong in that respect, particularly with regard to psychiatry, his own field. Szasz is another figure that was being read and influential in that respect. So I think when the bioethicists come on the scene that was a very widespread view of medicine and their ideas were drawn to the paternalism problem. Veatch clearly buys that from the very beginning. I never really bought it completely but I was coopted into it too. In so doing, the social justice questions were left on the outside. We knew that there were problems with access and things of that sort but those weren’t really big, looming problems. In fact, I think a lot of us, I have to admit this is true of me, thought that the access problems were fundamentally solved by the Medicaid/Medicare legislation. Once we got that working we would not have this social problem of insiders/outsiders in medicine. Our social problems would be reconstructing the inner medical world so that there were more patient rights, more patient autonomy. We weren’t going to have to worry about the justice questions. So in sum I think there were two things. One was the weakness of American philosophy in discussions of social justice and the other was centrality of the paternalism question. Also, this fits exactly into that, since so many of us were working in medical schools we were confronted with this problem of patient-
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Al Jonsen

physician relationship. We knew that the old medical ethics was fundamentally

patient-physician relationship oriented. And we wanted the new medical ethics to

be a refreshing of that old one, and the way you refresh it is you enhance the

patient’s autonomy. You made it into a therapeutic partnership. We were not in

settings where we could criticize the social structures of medicine very strongly.

Even the health policy activities that I was involved in early with Phil Lee, were

not really strong criticism of the social world of the institutions of medicine. It

was rather studies of how we could better cover people with insurance. How we

could better distribute physicians around the country so that rural areas were

served and that kind of stuff.

Swazey: I’m still struck though, and I accept historically everything you’ve said, but I think

it was Paul Ramsey, who in the mid-1970’s said one reason bioethics has focused

so on the individual issues is because the larger macro issues of social justice were

so intractable to moral reasoning. But as you said, there is such a long tradition in

both Protestant and Catholic moral theology of dealing with those social justice or

justice issues, and they certainly were big issues. Is that sort of an apologia or

what?

Jonsen: I don’t know. I think that Paul, in saying that, says one true thing and one false

thing. I think the true thing he says is that they’re intractable to moral reasoning
because all of those issues are so thoroughly involved in political and economic
questions. You can abstract from that when you talk about whether people should
tell lies or tell the truth, but when you talk about whether there should be free
medicine I think it’s true to say that is intractable to moral reasoning. You can
make a theory that’s great but it won’t have any reflection in the world out there
because of these huge interests. What is untrue in Paul’s statement is the
inference that there has not been a lot of good moral reasoning about social
justice. Paul knew all that but he still had the heart of a Protestant Methodist
preacher, you know? And for the Methodist preacher the question is
righteousness...personal righteousness. Paul knew Niebuhr. I don’t know what he
thought about Niebuhr, but he’s written about Niebuhr. He knew all those social
justice questions but I think he could never get out of that Methodist pastor view.

Swazey: Because otherwise, without knowing that context it reads almost like a copout.

Jonsen: Yea.

Swazey: Another thing that fascinates me is the proclivity to say that the health care
delivery, access, cost, etc., issues are policy and economic issues.
In the few minutes left today, in terms of future leaders of bioethics, you
were saying you don’t know them.
Jonsen: True I don't really know them. That's kind of tragic and it's my fault, I guess. I had leadership positions in the Society for Health and Human Values and after I was president there I kind of separated myself from that group, and that's the place you usually would meet them. Very soon after that the American Bioethics Association came into being and I didn't have anything to do with that. I felt that it was a wrong-headed development. I thought that it was being unfaithful to the old institution, to the Society for Health and Human Values. So I just kind of stayed out of it. Dan Wikler, when he first was promoting it, wanted to get me involved but I stayed very distant from it. And that would have been another place where I would've come to know younger people. So the two convening places I haven't been involved with for five, seven, eight years. There are people among the group that I have been dealing with of course, and one of them is Nancy Jecker, who's on our own faculty here, who's an extraordinarily bright young person. Her fault is that she doesn't get deeply involved in the clinical realities, or in the realities of what she working on, but as a theoretical thinker she is very good. I have a lot of respect for Eric Juengst as well, at Case Western. Eric is a quiet personality but he is a good, solid, dependable thinker who really looks carefully at the issues that he's dealing with. It's hard for me to go much further. The issue comes up here in talking about who's going to be my successor. For me, the young generation is still Dan Brock, and Alan Buchanan, and Dan Wikler, and John Arras. I think John is great but he's the middle
1473 generation. Those are all middle generation, see?

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1475 Swazey: They are now.

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1477 Jonsen: So, I don’t know.

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1479 Swazey: A lot of people that I’ve asked that question to have had trouble coming up with
names, and it’s not because they don’t know a range of people. But they’ve said
in part that however wrongly they start doing comparisons with, for example, the
young people who started Hastings, the young Bob Veatch’s, etc. And they’ve
said it’s probably not fair because we’re judging by what they then became. They
seem to also have a sense that so much of the foundational work and thinking has
been done, what role are the young people going to play?

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1487 Jonsen: That’s true, and they move into already established situations. They teach courses
where the content has been established. There obviously are certain people who
are working in forefront areas. The people working in feminist theory, people like
Susan Wolfe, in attempting to draw feminist theory into bioethics are plowing
new ground. Similarly, people who are going to be working in the justice area but
I can’t tell you who they are. It’s interesting to me when I pick up The Journal of
Medicine and Philosophy now, just like the one that came today, that I don’t know
any of the names of any of the authors. I think they may be doing interesting work, and they are perhaps better prepared than we were to contribute, but nobody stands out. I don’t see them. Maybe this is a broader phenomenon, maybe there’s a kind of an undifferentiated characteristic of young people in various fields. I don’t know.

I don’t either, but I think perhaps that as a field becomes a field, or a discipline, or whatever you want to call it, it does become more routinized, and it may be harder for the real outstanding people to come up to the surface.

Yes.

Sort of a depressing thought! It’s hard to think of a new kind of a bioethics institute one could create, a new type. We have The Hastings Center Report and its progeny. We have all the work on principles.

There’s a new movement to try to reintegrate religious thinking into bioethics.

That’s a major topic. I want to talk about it because that whole history is one I find very unsimple, very complicated.

(END OF DISCUSSION FOR THE DAY)
Swazey: Maybe you could start out today by giving me your perspective on the role that religion and moral theology have played in the development of bioethics.

Jonsen: The role of moral theology, and that’s the Roman Catholic term, or Christian ethics, the more commonly used term in Protestant denominations, had to do with several things. The first is somewhat speculative, and that is that the questions about the new biology and the new medicine were questions about life and death, and the meaning of life, and the control over human destiny, things of that sort. Those are, in a very general way, constant themes of religious ethics, attended to more or less throughout the traditions but always there. The Catholic church talks about what one has to do to attain salvation, the kinds of behaviors that you have to adhere to in order to be saved. That can get very picky, whether you have to go to church on Sunday, it’s a mortal sin to eat meat on Friday, and those sorts of things. Behind all of that, of course, is the question of the meaning of morality, the meaning of life; those were familiar enough questions to theologians. Whereas, they were not very familiar questions to modern philosophers, particularly moral philosophers. The people working in moral philosophy had, for several decades, paid much more attention to the parsing of sentences that made moral statements. “You ought to stop at a red light” was the kind of thing they were interested in. And so it was not part of the idiom of moral philosophers, and it was not part of the formal studies of moral philosophy at all in that era. So, in a
sense, the questions appeared quite natural questions to the theologians and quite foreign questions to the philosophers. A second reason was perhaps more practical or realistic, that is the early people who got into the field came from religious ethics and were established in it: Joseph Fletcher and Paul Ramsey coming out of that tradition; Jim Gustafson coming out of that tradition--they brought to it their general perspectives. Religious philosophy also has always paid a lot of attention to behavior and to practice rather than concentrating on ideas. The idea of the good fascinated philosophers; the leading primary work of moral philosophy in this century is G.E. Moore’s *Principia Ethica*, which is about the idea of the good. Religious ethics has been much more interested in behavior, what one ought to do, what one ought not to do. What ideals one ought to hold, how those ideals should be manifested in the form of institutions, and personal behavior and so forth. That made it congenial to questions that had to do with the practice of medicine, with the activities of science and things of that sort. I think that’s why the religious ethicists got into the field early and impressed it with their way of viewing things. In fact, perhaps I can come back to this when we talk about the relative relationship of philosophy and theology. Maybe I should say it right now. The religious ethicists brought some pieces of their tradition. The Roman Catholic moral theologians, for example, such as I was, had fairly worked out pieces that fit into the new questions of bioethics and that had been around for a long, long time. That is, it has been traditional since at least the 16th century to
consider questions of appropriate medical practice. Interestingly enough,
ironically enough, the Roman Catholic moral theologians always considered that
in their books when they treated the fifth commandment, "Thou shalt not kill,"
because the questions of medicine about life and death had to do with what
physicians could do or could not do to avoid killing their patients. So the idea of
ordinary and extraordinary means of care, for example, go back to the 16th century
in terms of the conceptual ways of working at those things. Similarly, a lot of
questions around abortion and contraception had been in the Roman Catholic
moral tradition for a long time. So what Catholics could do was, in a sense,
abstract lines of argumentation from those traditions that were not specifically
ecclesiastical or theological. It has to be recognized, as far as Roman Catholics
are concerned, that almost all of practical reasoning in Roman Catholic moral
theology was based on the theory of natural law, which meant that practical
reasoning was not based upon biblical interpretation, was not based upon
theological doctrines, and so forth. The only way in which theology plays a really
strong role in Roman Catholic moral theology in its traditional sense, which was
the authority of the church to say that this particular argument of natural law
reasoning is to be considered valid or invalid. The church claimed the authority as
a teacher of morality to be able to adjudicate natural law reasoning. But the
natural law reasoning is reasoning that Roman Catholic moral theologians would
say any human being, regardless of whether they are Catholic, or Protestant, or
Buddhist, or whatever, can understand. So when the Catholics came to bioethics they brought pieces of fairly well-worked out questions into the argument and at the same time they de-theologized them when they did that. Not just because they wanted just to communicate with the wider world but because that was their tradition, to use philosophical natural reasoning in dealing with moral questions.

With the Protestants it was a little different because natural law reasoning had been repudiated in the Reformation by the great reformers, although Calvin kept parts of it and respected it. But in general, there was a very strong trend in Protestant religious ethics to become much more biblically based. They of course, didn’t have the strong tradition of ecclesiastical authority, but the reading of the Bible as a document of moral instruction, the preaching based upon that, gave to most Protestant thought a much more theological tone. However, in the 20th century, particularly in the post-social gospel era that I was talking about yesterday, essentially from the 1920's on, when they plunged into a practical realm of social, political, financial and economic practices in the world, like “what should labor unions be doing?,” and particularly the questions surrounding the legitimacy of war, whether the church should be pacifist, they too began to make arguments about these moral questions that were much more arguments of reason rather than arguments of theological dictate. For example, the Christian pacifist arguments, were very largely biblically based, based upon New Testament texts, for example, in which Jesus appears to repudiate violence. And the anti-pacifist
arguments in the Christian church, made by people like Niebuhr, were not biblically based but reason based. And so you had an interesting similarity at the time the theologians began to get interested in bioethics. Both of them, Catholics and Protestants were coming at the issues with an appreciation of reason based argumentation, the Catholics because it had always been in their tradition, and the Protestants because it had been a relatively new discovery in their way of doing ethics.

So I think it’s a fallacy to say that the theologians abandoned religion, as some people have said. Stanley Hauerwas particularly, and now Tris Engelhardt, are saying that the theologians started out in this field as theologians and then they gave it up. They give different reasons for it. One is the practical reason of having to communicate with people who don’t share their faith. And the cynical reason is that the early bioethicists were employed by secular schools, and therefore couldn’t talk religious language. That applies to me: I’m a theologian hired by the University of California and I can’t go in and preach Catholic thought. So they say, “Well, that’s the reason why people like Jonsen gave up talking theology.” I don’t think, for the most part, the theologians of that era talked theology when it came to ethics. They talked arguments of reason. There were, at that time, several very, very interesting internal debates going on. In Roman Catholic moral theology there was a debate about the principle of double effect which was extremely far reaching. It wasn’t just the application that we use
in bioethics now about whether you can give pain killing medications to people
that are dying and thereby hasten their death; it was a much broader discussion
about the structure of moral reasoning. Richard McCormick was a very
prominent figure in that debate which actually originated among Catholic moral
theologians in Europe. And so that’s an argument about how you reason about
moral matters that are perplexing in which both sides appear to be right or wrong,
depending. In Protestant theological circles, at just about the same time, there was
a big debate about norms and rules. When you make a normative statement it’s
always a generality or a universality such as “thou shalt not kill.” When you get
down to the actual moment in which a decision has to be made whether to defend
oneself against an attacker, or whether to assist someone to die, how does that
general rule apply to the circumstances? And so the Protestants were debating an
issue about moral reasoning at the same time that the Catholics were debating a
question about moral reasoning. In neither of them is the question a profoundly
theological one. It is in its deep roots but for the most part it’s a question of the
logic of moral reasoning. To some extent in both debates they begin to touch the
edges of what moral philosophy was doing at the same time, because questions of
structure of moral reasoning were involved.

Swazey: In terms of normative ethics?
In terms of normative ethics. I think that’s also a reason why one of the earliest philosophers to get into the field got into it, namely Stephen Toulmin, because his approach to normative ethics was clearly concerned about this normative principle in relationship to actual circumstances. His early essay that had very widespread currency, “How Medicine Saved the Life of Moral Philosophy,” expresses that.

Then some philosophers began to drift into the field. Dan Callahan clearly is one, but it’s interesting that while Dan was a philosophy major at Yale and then did his doctorate at Harvard, he also came out of a traditional Catholic family. While he has never spoken as a Catholic with doctrinal background, he was very much permeated by it as one can see in his early book on abortion. The arrival of philosophers in the field really starts a little bit later than the theologians. If one looks at the events of the 1960's when ethicists begin to pop up at medical or scientific conferences, they’re mostly theologians at that point in time. Most moral philosophers, if invited to go to a conference to speak on discontinuing renal dialysis, if they were honest would probably say, “I don’t really have anything to say about that.” A few showed up and they did what philosophers are usually expected to do, like Abraham Kaplan of UCLA showing up at one of those conferences and making some remarks about the meaning of terms and the logic of argument, but it’s mostly the theologians that appear in the 1960's. In the early 1970's the philosophers begin to appear much more frequently--Callahan very prominently, Tris Engelhardt just having finished his philosophy degree and
his medical degree, Tom Beauchamp, Danner Clouser who actually shows up at the end of the 1960's. By that time the division between theology and philosophy was pretty much wiped out because the practical questions were very, very heavily on the agenda. The ethicists were paying attention to the dimensions of the practical issues, such as the definition of death and allocation of scarce resources.

You notice in the first great book in the field, in Ramsey’s *Patient as Person*, he starts out by saying that he is writing as a Christian ethicist but there’s very little theological thought expressed throughout that book. There are references to theological sources of morality, ideas of divine love and compassion, but all of the essays that make up that book are very strongly written in terms of moral reasoning. They’re logical arguments, the assessment of arguments justifying one course of action or another course of action. So while it’s a hard book to read and many people say, “Oh, it’s so theological,” it’s not theological at all. It has theological terms here and there but it’s really Ramsey’s logical mind working at these issues. I’ve written in an obscure essay somewhere, actually it’s in a festschrift for Jim Gustafson, that the ethics and the ethicists of the early era of bioethics were improvisers, the ethics was improvisation and the ethicists were improvisers. I try to analyze the idea of improvisation in terms of music, actually, where a pianist or a violinist in the classical concerto will take off from the themes and improvise on them and the improvisation is very largely creative within a set of general thematic presentations that have been built into the written
part of the symphony or the concerto. I think that is what bioethics was and still
is, is a form of improvisation in which people came out of traditions in which
there were certain sorts of themes, either the religious tradition, Protestant or
Catholic, or the philosophical tradition. And by the way, the philosophical
tradition was also somewhat diverse. We always think of it in terms of the logical
analysis approach, but there was also, in the 1960’s, the phenomenological
approach and the existentialist approach, both of which were kind of minor
streams in American philosophy, but still they were there. Bill Winslade, for
example, who did his philosophy degree at Northwestern, did it primarily under
people who were phenomenologists. That was a great center for American
phenomenology. So there were those other traditions too. People coming from
the world of ethics’ studies in both philosophy and theology had some very
general themes that their traditions gave to them, but when they came down to
dealing with questions that were posed by the new medicine, the new biology,
they improvised. They pulled pieces from here and from there. A number of
people were equally comfortable with philosophical and theological reasoning. I
told you yesterday I felt very comfortable in both idioms. Most people who came
from the Roman Catholic tradition never saw philosophy as foreign from
theology. There were a lot of resources about how to define ethical terms, how to
make arguments about ethics, so forth and so on. They drew from all of that and
improvised when it came to making arguments. So if you actually look at the
essays that were written for the National Commission, the essays written by
philosophers and the essays written by theologians look pretty much the same.
There’s no great recourse to biblical or theological reasoning, or even to
ecclesiastical authoritarianism such as it existed in the Catholic church. The
arguments in those essays look pretty much the same. If you didn’t know that Jim
Childress was a theologian, and that Kurt Baier was a philosopher, you wouldn’t
be able to tell by reading those essays.

Swazey: Apart from the fact that both groups were, as you said, engaging in moral
reasoning, does the fact that these papers were being written for a government
commission, also influence the extent to which they were explicitly drawing, or
not drawing, on religious perspectives? And was there a sense that they needed to
be in “secular” language?

Jonsen: Well, I don’t know that. I think the only test of that was, did they write differently
when they wrote for different sponsors? And they didn’t. Jim Childress’ material
was published in other places, as some of the initial literature about bioethics, and
it looks the same. In the Western theological tradition, with the exception of a
more fundamentalist approach, I think it’s almost inevitable that after some
theological premises are stated, the theologians will move down to logical
argumentation. There was also a big debate, largely within Protestant thought, but
somewhat reflected within Catholic thought during the 1950's and 60's, about
what makes religious ethics distinct from any other ethics. There was a lot of
literature poured out about that. Jim Gustafson was a major contributor to that
debate. There was a group of theologians in England, for example, very much
entranced by and affected by the logical positivism or the logical analysis
approach that was so favored in the English universities at the time, who were
writing theology in ways that they felt was compatible with the logical
philosophical approach. Their question was, “what is it about theological ethics
that makes it any different?” And different sorts of arguments came up. It’s the
commitment of individuals, it’s the question of the recognition of an ultimate
judgement on one’s actions, things of that sort. But it isn’t the content that’s very
different. It’s hard to find content that’s different. On certain pieces, yes. Roman
Catholic thought on contraception is probably the most idiosyncratic piece of
Roman Catholic theology. Abortion not so much so, because as we know from
subsequent developments, the anti-abortion arguments cut across all religious and
even secular lines. It’s not as if you can say that pro-choice is all secularist and
pro-life is all religious. Contraception is a different matter, and I wish I could tell
you why. I don’t really know why... in any definitive way. But the argument, how
does religious ethics differ from ethics done in a secular way, was a vital
argument just about the time that bioethics was coming into being.

Swazey: I know Jim Gustafson made a statement, it may have been in his book on
Theology and Medical Ethics, that he thought theological ethics would not make a
major contribution to medical ethics because the arguments and principles could
be stated in philosophical secular terms, essentially just as well.

That’s exactly right. That’s in his Marquette lecture on medical ethics and
theological ethics. That’s true and that’s the position that he takes. He believes
that for a believer with a theologically grounded faith there will be perspectives on
the meaning of life that are not shared by people who are not believers, and that
there may be motivations to act in ways that non-believers do not share. But those
perspectives have little to do with the substance of the arguments about the
rightness or wrongness of action. You can make the same arguments
theologically or philosophically.

What you’re saying in a nutshell, I think, is that after the great initial cohort of
figures like Ramsey, Joe Fletcher, Jim Gustafson, Dick McCormick there have
continued to be major figures in bioethics who have come out of a religious
tradition but essentially are writing like the philosophers are, because they are
doing the same types of improvisational work, and engaging in moral reasoning.

I do feel that. There’s clearly now a group of younger people who come from the
theological background who are vitally interested in discovering a way in which
theological argument may be more cogent in actually affecting the analysis of particular problems. Alan Verhey, who is a Gustafson student, is very concerned about that. Kevin Wildes is very interested in that; he is an Engelhardt student. They are trying to present argumentation that would make a theologically distinct form of bioethics. I haven’t been particularly convinced by their approaches. But I also have to admit that I haven’t read a lot of their work because for me that question is a kind of settled question.

Swazey: What about the Jewish traditions? I know there has been a long tradition of Orthodox Judaism dealing with these issues, but as bioethics began, it doesn’t seem there was a major role of orthodox, or conservative, or reform Judaism. Is that because they were primarily writing for their religious communities?

Jonsen: That’s my impression, that Jewish thought, which is often times fascinating and compelling, has traditionally been written for the Jewish audience. Once in a while a Jewish author like Abraham Heshel or Martin Buber caught the fancy of the wider world and had significant impact. But for the most part, the writing was within the community and that’s a reasonable thing because it’s a position of Jewish thought that Jewish law—you know they prefer that term to talking about Jewish ethics—that Jewish law pertains to Jewish people. There is a parallel to the natural law tradition within Judaism which suggests that there are laws that are
common to Jews and non-Jews. But that's not a really big part of it. So the work of the Jewish scholar, the Rabbi writing about ethics, is largely to speak to their own people. Secondly, rabbinic writings are a very unique idiom which is hard to translate into secular thinking. The importance of the reference to traditional authority, for example, will make the reading of an essay on some bioethical subject written by a Jewish scholar impenetrable to a non-Jewish reader. The reference to Rabbi this and Rabbi that, in particular the very close analysis of terms, of language, which has a parallel to Roman Catholic casuistry in a way, is often times done by reference to traditional meanings of words and things of that sort. It's very hard to translate that idiom. Certain people early in the bioethics world began to do that to some extent. Fred Rosen was perhaps one of the most visible of the translators between the strict rabbinic and the practical world of medical decision making. Several of the Rabbis, like Bleich and Tendler, have gotten close to doing that too. Although it's interesting, Tendler has just edited a collection of the opinions of his father-in-law who I think was the Chief Rabbi of Jerusalem where you can see Tendler's preoccupation with the properly Talmudic form of argumentation. So I think that's the reason why they stayed somewhat on the sidelines.

Swazey: There seems to be a florescence of Jewish medical ethics conferences now.
Jansen: Yes, I don’t know why that’s the case except that it may be that it’s a part of this more general phenomenon of the interest among younger Jewish people in the traditions of their faith. And since the medical community in the United States has a very high percentage of Jewish members, I think that general interest in the return to the sources of Judaic belief may have a lot to do with that florescence. The San Francisco conference...I forget the name of the Rabbi who has put it on, remains very heavily, really almost exclusively, focused on Jewish issues and draws very, very largely on the Jewish medical community for its speakers rather than just the Rabbis. It’s interesting that the synagogues...I went to a meeting at B’nai B’rith just a couple of weeks ago on life support that drew a big audience in which a Jewish educator, not a Rabbi, and a Jewish doctor both presented their points of view. I was astonished at the number of people in the audience.

Swazey: Quite apart from how you’re assessing the caliber of some of the younger people trying to reintroduce theological ethics into bioethics, given the pluralism of American society do you think that is a drive that could succeed? To move more from the moral reasoning framework to the more explicitly theological dimensions.

Jansen: I don’t think it will succeed. I think there is one place where it might succeed and that’s within fundamentalist Christianity as it becomes more intellectual. As you
know, the history of American Christian fundamentalism is a fascinating, complex
one. It's main streaming itself now, and large numbers of its participants are
educated and intelligent people who are interested in developing more articulated
positions that are in conformity with their beliefs. And so I think that there may
be a Christian bioethics created within that sphere.

Swazey: Do you think it would move outside of that sphere though, or would it be more
confined like Jewish medical ethics has been?

Jonsen: I think it would remain more confined. I think it would. It's interesting that the
title of the new journal that Engelhardt, Wildes, and Stanley Hauerwas put
together, is Christian Bioethics and the subtitle is A Non-Ecumenical Journal.

Swazey: That's pretty explicit.

Jonsen: Yes.

Swazey: You've said in our conversation and certainly written that you don't think that
philosophical theory has had a great role to play in bioethics. Could you expand
on that a little bit?
First of all, I don’t think that there is a very clear or strong concept of theory in moral philosophy; there never has been. One can read all of Plato, or one can read all of Kant and call it theory if one wishes to do so. But the idea of what theory is supposed to do in ethics has never been very clearly articulated. John Rawls makes a very good move in the direction of articulating what theory is supposed to do. But theory means very different things to different people working in moral philosophy. I’ve got five or six different quotes from moral philosophers in *The Birth of Bioethics* that show very different approaches. So given the fact that theory has never had this very powerful conceptualization in moral philosophy, is one reason why it doesn’t mean much. The most common use of the concept of theory in moral philosophy is to designate the form of reasoning which establishes the validity of moral arguments. For most of the 20th century that has meant the theories that established the validity of arguments about obligation, and for the most part that’s been the debate between theories that are consequentialist and utilitarian in scope and theories that are not. There is no doubt that an enormous amount of philosophical ink has been spilled over the structure of utilitarian theory. The others, the “not” theories, the non-consequentialist or sometimes called deontological theories, are scattered all over the place. Even the favorite book of people who adhere to the “not” side, which is Ross’ *The Right and the Good*, is not a very clearly articulated basis for deontological reasoning. The utilitarian theory has been so punctured over the years and it keeps coming back to
life, in a variety of ways, but critical analysis has just found it thoroughly unsatisfactory in many, many respects.

Swazey: Medicine, I think, has always been particularly congenial to a utilitarian approach.

Jonsen: There's no doubt that's the case but as a philosophical theory it's very weak. And yet, as I say, it keeps coming back. So that's the second reason why theory is not very important. There isn't any great agreement about what those theories are and how they ought to function. And when you read Beauchamp and Childress' Principles, they say, "Well, here are these two theories of obligation and here are the pros and here are the cons but it really doesn't make much difference."

Arguing about particular cases is going to pretty much end up the same way regardless of what theory you take. Now there are points at which that's not entirely adequate. You can push arguments back to a point where you say, "Well, you've got to decide whether you're going to be utilitarian or not be a utilitarian."

But again, you get into a circle because it's not entirely clear what it means to be a utilitarian. The third reason why theory has not played much of a role is that the relationship between theory and practical judgement is very unclear. That's the point that I mentioned a few moments ago in talking about that debate among the Protestant religious ethicists about deeds and rules. It's the general problem of how you move from general affirmations to particular statements of rightness and
wrongness. That was the issue that drove Stephen Toulmin and I to begin to explore casuistry, because casuistry is an attempt to deal with the rule-decision relationship. Sometimes it doesn’t look like that because there is so much attention paid to particular cases. But basically it’s a question of how rules apply. The application of rules to particular decisions is highly circumstantial. If you take that statement in its most radical form you’re into situationism. And if you take it in a more restricted form you are into casuistry, which says the question is how do you analyze circumstances in relationship to general rules, or how do you analyze rules in relationship to particular circumstances? It occurred to many of us early on that the interesting features of bioethics were its cases; that when we talked about discontinuing life support it really came down largely, to use the title of that famous play and film, “Who’s Life Is It Anyway?” or what kind of life is it? All of those are questions that are casuistic. Who is this person? What is their life at this point in time? What is it that the medical intervention can actually do for them? And a whole range of other questions like what costs are involved and so on. At that point the perception is that any theory as such is much too general in scope...much too general to deal with the kinds of questions that are of interest in bioethics. Again, that’s Stephen Toulmin’s “How Medicine Saved the Life of Ethics,” which is an essay that he wrote when he and I were in the middle of doing the casuistry book. So I think those are three reasons why theory has not been of much interest. It’s interesting there are a couple of efforts at general theories, like
Engelhardt’s book and Bob Veatch’s and so forth. They are interesting but I don’t think they’ve had much impact.

Strangely enough, it appears that Engelhardt’s book is generally read as a standard example of American bioethics by Europeans. What should you read to know what American bioethics is? You read Engelhardt. That was my impression when I interviewed a number of people in Europe, that they had read Engelhardt and they hadn’t read anything else.

That’s kind of giving them a skewed perception....

Very much so.

Does that mean from your perspective that the current raging debate about principlism and alternate theoretical constructs is not terribly relevant to doing bioethics?

I think it’s relevant. Notice that the debate is not about theory and practice, it’s about principles and practice. There’s no way in which you can get away from
principles. You can be very cavalier about theory and ethics, I think, but you can’t
get away from principles because principles are always thrown into the debate by
anybody arguing for one way or another. I think the debate about principles is
overdone. People are finding things to argue about that I don’t think are worthy of
argument. But careful articulation of the principle/decision relationship is
something ethicists always ought to be doing. It’s going to come out differently.
In Aristotle, for example, there are two quite different approaches to that problem
depending on the way in which one reads the Aristotelian text. One is the kind of
syllogistic reasoning, where you go from major premises stated as general
principles, to particular conclusions. And the other is his argument about the
perception of what is right in a particular situation. Those can be seen either as
complementary or they can be seen as contradictory, or as if he’s written one
when he’s awake and the other one when he’s asleep, or one when he is sober and
the other when he is drunk. So that particular debate ought to continue on in
moral philosophy. Do we have ways of arguing syllogistically from principles
that really function well, or do we have to rely on radical intuitions into the
rightness of circumstances or cases? The principlism debate, to the extent that it’s
a continuation of this kind of classical internal discussion among moral
philosophers, is a good thing.

Swazey: Where does law, American jurisprudence, fit into philosophy...moral
reasoning...in bioethics? As you know, there certainly is a spectrum from the
George Annas view that bioethics is going to disappear because it’s in the end just
to broader perspectives like Alex Capron’s.

Yes. Well, there are different points of view that one can take about it, but I think
that I will always say that law and ethics are different. They have different
objectives. They have different sources, different purposes, but the ethical
decision or the ethical question in any particular case has to have reference to or
take account of what the law has established or would appear to establish. In the
most fundamental sense, the problem of conscientious objection is the most
radical demonstration of the law-ethics relationship; it’s when somebody says, “I
can’t obey this law in conscience.” If law and ethics were the same thing that
question would never come up. I think most of us repudiate legal positivism.
And then the question is: Can we ethically evaluate the moral relevance of the
law? The law might put you in jail but the question is: Is it good law, is it right
law? So I think you always have to have a distinction between law and ethics.
There’s no doubt that American jurisprudence and bioethics have many
interesting points in common. That has to do with the history; that is, Anglo-
American jurisprudence grew up within a world of thinking where legal reasoning
and ethical reasoning were very parallel, and that’s historically the case. One can
find that most of the forms of legal argumentation are imitations of forms of
ethical argumentation. So I think that George exaggerates. I think that bioethics
and the law about bioethical issues are in an interesting conversation but it seems
to me that many of the great decisions made by the courts have really paralleled or
imitated ethical argumentation. That’s not entirely the case because American
court decisions have to follow certain sorts of rules and you have to pay attention
to precedent very, very rigorously. Precedent is not a feature of moral
argumentation but there are many parts of the great legal decisions that could just
as easily be thought of as moral argumentation. Then there’s another question
too: if you construct good moral arguments about things, whether or not you ought
to attempt to make those legal formulations as well. My tentative answer is,
probably not.

Swazey: Does that bear on the role of the ethicist as an expert witness in legal cases?

Jonsen: Well, I don’t know. I think that there’s a fairly restrictive role for the ethicist in
legal cases and that is to simply give testimony as to what the prevailing opinion
is within the ethics community, relative to a particular issue. So that if a physician
defends himself or herself in a particular action by saying, “What I did was
ethical,” one response to that is, “Well, whose ethics?” If he says, “My ethics,”
then we don’t have much to say. But if he says, “This is the ethics of the
profession, or it’s the prevailing ethical opinion,” then an ethicist can come in and
say, "Well, it is true that if you read all the articles about withdrawing life support, you'll find it very largely going in the direction of Dr. So and So says..." Then the court's going to have to do what it wishes to do with that kind of opinion. It seems to me that it is, in a sense, the ethical parallel to expert opinion in medical matters. But it isn't that the ethicist makes a judgement as to whether the legal provision, if there is one, if there is a statute, is right or wrong. I don't think we ought to do that.

Swazey: That certainly, as you know, is a fairly debated topic.

Jonsen: Yes. I've got a case now that illustrates that. It's a question of resuscitation of a newborn in which the attending physicians, at the time of birth, judged that resuscitation was not appropriate; they were unable to consult with mother and father at that point. They decided not to resuscitate, and the baby, in fact, did not die immediately and then a resuscitation was attempted quite late. I'm asked to testify on whether the initial decision not to resuscitate is in conformity with prevailing beliefs in bioethics.

Swazey: The major players at the bioethics table have been philosophers, religionists, lawyers, and medical professionals. What do you think accounts for the long prevailing tensions between bioethics and social sciences?
I think in part it comes from the majority of the traditional bioethicists not knowing anything about the social sciences. I have always thought of myself as an exception to that. I didn’t mention to you the other day when I was talking about my history that I was an anthropology minor during my college days. And I did two summers of field work on the Crow Reservation, and really wanted to go into anthropology. At one point in time I was all lined up to go to Harvard for anthropology. So I read a lot of anthropology and even taught one course in anthropology when I was teaching at Loyola University.

I think, though, you can say the flip side is also true, that there are not many social scientists who have any grounding in philosophy or theology.

Yes, I think it was a mutual ignorance of each side. I think, of course, that there’s an ideological difference to the extent to which they do know about each other. Certain people working in ethics probably have viewed sociology and anthropology as ethically relativistic. On the other hand, people in social sciences have viewed philosophers and theologians as ethical absolutists, which was empirically absurd. So I think that there was probably this ideological difference that said, “What do we have to do with these absolutists, and what do we have to do with these relativists?,” which is false because you’ve got as many relativists in the philosophy camp and vice versa. I think there was that relative ignorance and
the ideological perceptions about the two. And I also think, as I mentioned briefly
in the book, that the really remarkable efforts to bring the social sciences into
medical education that were moving ahead in the 1950's and 1960's were
overshadowed by the immediate popularity of the ethics. That was, I think, in part
due to the fact that the doctors recognized that the ethics was something that was
already within their tradition anyway and that it had something to do with practice
that was fairly direct. Whereas, all the sociologists and anthropologists were
doing was telling them what they were doing, and they weren’t interested in that.
They didn’t see that as shedding any light, which of course is stupid. People like
Anselm Strauss, for example, whom I knew very well, I think was deeply hurt by
the way in which his role at UCSF was marginalized.

It’s been a fascinating sort of contemporary historical sequence in medical
education, because all of it’s been done in the name of “humanizing” medicine by
various disciplinary sort of parachutes.

Yes.

Is another possible factor that a lot of the schools of moral reasoning in bioethics
didn’t see a need for empirical information? It has been at a level of abstraction
where empirical data didn’t much matter. Alex has made the same argument
about a lot of policy: that it's made in the absence of, or despite empirical data,
which is seen as sort of irrelevant.

Jonsen: I'd say there was something else to it than just a lack of relevance. I think it was
much more a question of the philosophers and theologians thinking that they knew
what the facts were. They didn't need anybody to tell them more. I think there
was kind of an arrogance when they came into bioethics. Many of us are proud of
the fact that we came in and actually were there when these things were
happening. We thought we knew.

Swazey: One memory that has always stayed with me is the Hastings task force on
newborn intensive care. I was on that for awhile. I went to the first meeting and
looked around and said, "There aren't any neonatologists in this group." And the
response was, "We don't need any, we have physicians in the group." It was Bob
Morison and Will Gaylin. And me as a social scientist, that didn't cut it.

Jonsen: That's appalling, it really is! But that's true. I respect Bob Veatch's work very
much but Bob's never spent any time in the clinical setting. And so maybe if I say
people in bioethics thought they knew all the facts, I'm really referring to myself.
Back in the days when I was first starting out, there were some
sociological studies that I read and hated. I never could appreciate Freidson's
work. But I was incredibly enriched by Anselm Strauss’ work. I really learned a lot from Strauss and from Diana Crane, in particular. Your books with Renée were very illuminating to me. I guess the difference for me is that it seemed like Freidson was sitting there thinking this thing out about professional domination and then going out and giving some examples of it and refining the idea and so forth and so on. Whereas, these other books were really rich with the sense of what was actually going on. So I couldn’t imagine doing bioethics without that sort of thing, although I never systematically found a way to include it. Some of my students, early on, wanted to do bioethics and sociology and anthropology, like Barbara Koenig, and the person who did that nice book on neonatal intensive care, Rene Anspach. That had a lot to do with how we think casuistically. When you have a good sophisticated analysis of such things as the levels of power within a particular setting, not in the big overall world that Freidson was talking about, but in this nursery where the physicians and the residents are relating to each other, and somebody describes that, then it becomes casuistically relevant.

Swazey: It seems to me that there is a lot of synchrony between casuistry and participant observation.

Jonsen: That’s right. I think there’s more natural affinity between casuistry and participant observation in the social sciences than there is between casuistry and
narrative ethics which people are trying to do today. Narrative ethics, to me, rambles on and on and on. Participant observation essentially says, “You can ramble on and on and on, but you’ve got to find structure.”

Swazey: Do we have time to talk about clinical ethics?

Yes.

Swazey: You certainly had a good review of the fourth edition of Clinical Ethics in The New England Journal. The first broad question is what you see as the role of the person who’s called a clinical ethicist. It seems to me they obviously are not always dealing with the dramatic life-or-death decision type of case.

Jonsen: My view of clinical ethics and clinical ethicists is obviously shaped by my own experience. I believe that a clinical ethicist is an educator. I came into this kind of work as a professor of ethics in the medical school, realizing that we didn’t have an entrée to students by way of formal courses. It seemed to be a good thing to try to educate them at the level of their clinical experiences. As I mentioned to you yesterday I had a very good entrée in neonatology, and I had a very good entrée into the intensive care unit, and also in the cancer service and in high risk pregnancy groups. The educational role that I was playing there was to simply
help everybody involved in the situation work through the ethical aspects of cases that came up. So it was, in my view, clinical education with regard to ethics. And the structure of the book, *Clinical Ethics*, came out of that experience. It was an attempt to structure conversation in a way that would highlight and focus on the ethical problem in a case. It was almost always in the presence of several medical students doing their clerkship, more house officers than students usually, and the nurses and the attendings. But it was largely educational, so I never thought of myself as being a decision maker or giving people advice about decisions. It was simply to try to sort out the various features of the case that had some bearing on the ethical problem that people were thinking about. A second source of the structure of that book was in the initial Ethics Committee at UCSF which the chancellor had asked me to chair. We found ourselves, in those early days, without any way of giving structure to the kind of cases that we were asked to review. So the idea of what has come to be called “the four boxes” in clinical ethics came out of trying to give structure to a case that would allow people to look at all its features. So I’ve always thought of clinical ethicists as educators, not as advisors, not as consultants.

Swazey: Including patients and families in that educational orbit?

Jonsen: Well, I have not done that personally. I think there’s a good case to include
families but the reason why I have not done it habitually, (I've done it from time
to time) is that I strongly believe that the relationship between the physician or
whatever health care provider it is, and the family-patient that they were dealing
with, that the relationship needed to be very clear and that I shouldn't intervene in
it. So I felt that if I could help the health care provider formulate the issues, that it
was up to them to bring those to the family. It would happen from time to time
that the providers would say, “Let’s bring the family in and talk with them about
it.” I would always be glad to be there but I didn’t want to be the primary
spokesperson. I think that’s the doctor’s job.

Swazey: Did you generally have a fairly high level of confidence that after you had done
your educator role with a physician he would in fact be able to lay out those issues
for the family?

Jonsen: I never knew, I never really knew. I had confidence in the people that I used to do
this with regularly. With the ad hoc consultations you never knew what it was
when they went away and they’d say, “That’s great, that’s a great way to analyze,
a good way to put it.” How that actually came out at the next phase, I don’t know.
And I’ve never kept a record of it but I do know that on occasion I would hear
from other parties like the nurses saying, “Dr. so and so walked out of here saying
he was going to do such and such and he did just the opposite.” More frequently
than that I think...what happens is that the analysis given in these consultations
seem pretty good to everybody but the circumstances would change fairly rapidly.
The patient would get better, or the patient would die, or whatever, or something
new would come along that would change the circumstances. So I thought of it,
again, as an exercise in improving people’s ability to perceive what was at stake in
these questions. I think a lot of people have learned that perception and do learn
that. How they actually bring it to bear in a real situation, I’m never quite sure of.
I know now that in a number of places it’s being used as a tool to explain to
families what the situation is. I was out at a big nursing home the other day where
they said they have used “the four boxes” for years as their format for explaining
to families what the situation is. They sit down with the family, they go through it
with the family, they fill out “the four boxes”, they give the family a copy of it.
Then if an issue has to be discussed, like resuscitation, the family comes back and
says, “Let’s look; let’s see what’s changed.” Children’s Hospital here and its
hospice service uses it that way. St. Paul’s Hospital in Vancouver in the critical
care unit, uses it. I never conceived it in that way and yet it seems to be very
valuable in simply laying out what the case is.

Swazey: I would think it would be particularly useful in a hospice unit or a long-term care
facility where you have interactions over time as opposed to two days in the
hospital.
Yes, that’s right. So I don’t have a very romantic view of clinical ethicists. I
certainly don’t see them as going around with white coats second guessing. They
rarely have the scope of knowledge necessary at the clinical level to be
particularly helpful. They bring two things to bear if they do it well. The first is
some sort of clear and very practical analytic method, whether it’s Dave
Thomasma’s ethical workup or the four boxes, or whatever. They’ve got some
way of doing this in an unobtrusive and subtle way of ordering the issues to put
the focus on what the ethical problems are. And the second thing they bring to
bear is a treasury of other cases that are like this one. That comes either from their
own experience with similar cases, or from the literature, or from the law. So that
if you’re a good clinical ethicist, you tap into that store of information which the
best clinician may not have. They usually have their set of experiences
themselves but they don’t have the kind of precedent view of cases. Also,
ethicists can refer to certain sorts of arguments that have been made one way or
the other. I gave grand rounds to orthopedic surgeons the other day. And lo and
behold, in the question period somebody brings up the Lorber criteria. An older
physician said, “When I was a Fellow back in the 1950’s, I studied in England.
There was this physician in England that was setting out these criteria for surgery
for kids with spina bifida.” And he went on to draw some conclusion about it and
because I knew Lorber and his work I was able to put that whole thing in context
right away.
It doesn’t seem that long ago but I guess it was!

Yes it was.

So having said that, who should be eligible to be a clinical ethicist, or do clinical ethics? What competencies?

First of all, it ought to be somebody who has common sense and humility. I think those are the primary affective characteristics. Well, common sense isn’t affective, but humility is affective. And I think it ought to be someone who has mastered the extant and relevant literature. There is a canon that it’s important to have hold of.

Canon of cases as well as moral reasoning?

Yes, and theory is not a part of that canon.

I hear you!

And then I think you have to have a practical frame of mind. That is, you cannot leave that sort of encounter by simply saying, “Well, this is a tough problem,” or
make the problem more complex in people’s minds than it was when they came in. I remember Larry McCullough saying years ago at a meeting, “I was trained as a philosopher, and a philosopher’s job is to make problems more complicated than they appear to be.” You can’t do that as a clinical ethicist.

Swazey: That certainly is not what either care givers or families need.

Jonsen: No, by no means! And it indeed may be complicated and one of the first things you do is to disabuse people of the simplicity of the case. But you can’t go away leaving them with this open-ended sense of “there are all sorts of options out there and I don’t know which is better than another.” You should give people a sense that there are options but they are valenced ones. Each option has a set of arguments around it which give it a greater or lesser valence in the minds of the people who are listening to it. So when you go out and speak with a family, you may say, “Well, the primary thing is what the family decides, and here is what we think we ought to do.” But when you offer the family these options, give them some sense of the strength of those options.

Swazey: So somebody who comes out of one of the burgeoning number of masters programs in bioethics, are they ready to be a clinical ethicist?
Probably not. I would imagine that the first thing that they would do is to feel that they have the tools to do that sort of thing but they don’t, because they probably don’t have the humility. There probably, ideally, ought to be apprenticeships and mentorships in clinical ethics, which I guess don’t exist very much. So that someone who has achieved a reputation for doing it well can pass on, in a critical way, the kind of techniques that are useful. If you go back to what I said in the beginning, I think of it as an educational activity. Education has its techniques.

Certainly, it seems to me, if anybody is going to make it even more complicated than it is, it’s going to be the fledgling person with their newly minted MA who has to impart every nuance he or she can think of. Which I think most of us do when we teach for the first time. “Boy, we’d better give them every nugget we’ve ever learned or we’re failing.”

Everything, yes. You remember when you start teaching and you draw up a plan for a lecture and it’s always four times longer than the time you have.

Absolutely, so you speak very fast! Unintelligibly!

Since a lot of those people with MArs in bioethics are health professionals, that’s probably an additional problem because particularly physicians, almost
exclusively physicians, will go into clinical bioethics with the same kind of
authoritarianism. So they will lack the humility.

What about the certification-licensure debate? I guess I’ve never been able to
quite figure out how you would certify somebody.

I’m not a great fan. I haven’t read the certification report that Bob Arnold and
others did, so I don’t know what they say. I’ve never been a strong fan of
certification in that sense. We do give a certificate, but the certificate is simply a
way of saying a person has had such and such a block of education. It doesn’t
certify the set of skills that are necessary to do ethics consultation or clinical ethics
because those skills go beyond the educational, as such. I rather think that it will
get sorted out. There’s a lot of sorting out that goes on in our world of health
care. People come, and no matter whether they’re big surgeons or techs, and they
get tested and their testing pushes them aside or brings them to the center. I think
that’s what will happen with a lot of these people. They’ll go out and some of
them will do it well and they’ll be acknowledged, and others will be pushed out.
I’ve seen that happen; there are people who started out in the field and the
characteristic they had was a kind of an imperiousness, that they knew everything.
Then the next thing you notice...I’m talking about lay persons...next thing you
know they were consultants. They were no longer employed by the place that
employed them but they were private consultants, and then they disappear from view.

Swazey: That’s a good eliminating process...natural selection.

Jonsen: Yes, it’s natural selection. I hope it will work that way.

Swazey: Time will tell. Let me ask you a quick final question. Where do you see bioethics going in the future? Does it have new areas to get into?

Jonsen: I could simply say, apres nous le deluge. I think the mining of old subjects does take place within a context of new developments, to some extent. There is a history to these things. It isn’t just going over old territory, the territory changes to some extent. I think in the area of death and dying, which is a constant, we have seen changes in the social setting of those problems and in the technological and so forth. So that area will, I think, be a continual issue. I think, in general, that bioethics will remain around simply because of the complexity of the health care world. It is, in a sense, a creature of bureaucratic complexification. I suppose it’s a kind of a Weberian phenomena. The system has gotten so big and so complex that this little bioethics thing kind of grows on it, taking up a set of questions that are urgent, real questions that nobody else has the time or the
assignment to take up. I guess that’s the Weberian part of it, that bioethicists have
an assignment to take up a set of questions and to keep producing responses to
them. And I think the managed care phenomenon, which we’ll probably be
struggling through for at least ten years, will give a certain amount of space to the
bioethics activities. If we do have a patients’ bill of rights passed by the
Congress, that’s going to mean a certain amount of business for people in
bioethics because all that stuff will have to be turned into policy and applied and
so forth. And it’s natural for somebody to say, “Let’s get an ethics person to do
it.” The managed care people are already getting ethics people to do it! If a
patient’s bill of rights isn’t passed, all the problems that it was supposed to
address will still be there. That also leads the way to having some people doing
this general bioethics set of activities. I think the genetics advances and new
things in transplantation, like xenotransplantation, will also provide a set of
issues. And I think that the medical schools will continue to do what they have
always done, sponsoring teaching. And then finally, I think that there is, at the
present time, for the last few years, a growing interest in ethics in a lot of other
places. Bioethics is the grandparent. Journalistic ethics, and business ethics, and
ethics in the arts, and all this kind of stuff is starting to happen and getting
formalized within the university settings; something similar to what happened to
bioethics 25 or 30 years ago is starting to happen in those areas. And among those
people, there is an interest in learning what bioethics has learned in order to bring
it to bear in their setting. How much do you have to have of formal ethics? How much do you have to be a philosopher? We’ve got a nice little group of people here doing ethics in other places and we communicate and talk about those things.

Swazey: Sort of an ethics across the professions.

Jonsen: Yes, we call it The Ethics Alliance. And so I think that will also contribute to the continuance of this grandparent of ethics in the professions. I think it will be around and I think that it will change with the changing health care scene, with new developments in technology, but it will also change with the growing introduction of feminist ethics. I think that the cross-cultural issues are interesting enough and fascinating enough that it will bring some fresh thinking into the field and expand it; that’s very much on the fringes now. That’s a rough cut.

Swazey: Sounds like a reasonable one, it will be interesting to see. You have certainly given me a great deal of time, and thought, and thoughtfulness.

Jonsen: It’s my pleasure, Judy. I’ve enjoyed talking with you very much.

END OF INTERVIEW