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1 March 11, 1999. Interview with Ruth R. Faden, PhD, Philip Franklin Egley Professor of
2 Biomedical Ethics and Director, The Bioethics Institute, Johns Hopkins University; Senior
3 Research Scholar, Kennedy Institute of Ethics, Georgetown University. The interview is being
4 conducted by Dr. Judith Swazey in Dr. Faden's office at Johns Hopkins.
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6 *Due to a taping error by the interviewer, the first part of the interview with Dr. Faden, dealing*
7 *with her family background, education, and entry into bioethics was not recorded. The following*
8 *summary of these topics are from the interviewer's field notes.*

9 Family background. Ruth Faden, who is 49 years old, was born in northeast
10 Philadelphia near Oxford Circle. She has no siblings. Her parents were Holocaust survivors, so,
11 Ruth said, she had "two worlds growing up." Her mother was pregnant with Ruth when she
12 arrived in the United States. Her mother was from a small town in Poland near Cracow. Her
13 father was a furrier, like his father had been in Belorusse. Her father eventually opened his own
14 small furrier store in Philadelphia. Her mother worked as a seamstress. Her parents were
15 divorced when Ruth was 12. She described her mother, who died 12 years ago, as "she was my
16 gift."

17 Ruth said she was "sort of" brought up religiously Jewish, but primarily culturally
18 Jewish. Her parents kept a Kosher home, and she went to both Hebrew school and Jewish school.
19 She's not sure how deeply her religious upbringing influenced her subsequent work, but said that
20 "it is different when you know about the Holocaust from the age of 2 on." Her father, until
21 recently, did not talk at all about the Holocaust, but her mother was "a living spokesperson." "My
22 mother made all my relatives who did not survive very real to me." Her parents were on the "left
23 side of most issues. My mother's heroes in American politics were Henry Jackson, and Adlai

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24 Stevenson. My father was fiercely pro-American.”

25 Education and training. Ruth went to Northeast High School in Philadelphia, where
26 the documentary film by Weisman, called “High School,” was filmed. She noted that Bernie Lo
27 also went to Northeast. It was a very large high school, with 1200 in her graduating class. Her
28 guidance counselor, Ruth said, did not have confidence in her academic ability, and
29 recommended that she aim for being a nursery school teacher. But Ruth had higher academic
30 aspirations, and wanted to go to the University of Pennsylvania. She was not accepted initially,
31 so went to Temple for a year and, after a perfect academic record, transferred to Penn. Her
32 undergraduate major in American Civilization “sort of came about by accident.” Her boyfriend,
33 who later became her first husband, suggested she might enjoy taking a course in American
34 studies, which she did and then majored in American Civilization. After receiving her Bachelor’s
35 degree in 1970 she had planned on getting a PhD at Yale in American Studies, but her husband-
36 to-be was in Chicago at medical school, so she ended up getting a masters at the University of
37 Chicago in a program called General Studies in Humanities, which was the closest she could find
38 to American Civilization or American Studies. Ruth got her masters from the University of
39 Chicago at the end of 1971.

40 When asked why she had shifted from her American Civilization/Humanities studies
41 to a Masters of Public Health degree, she explained that she was 19 when she was married, and
42 said that when she moved to Chicago she needed a job. She saw an ad for a job in the obstetrics-
43 gynecology clinic working as a technician, which primarily involved being in the examining
44 room with the physician while the patient was being examined. This was before the Roe v. Wade

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45 decision, and Ruth said that she started doing family planning counseling, at a time when the
46 counselors were not allowed to discuss abortion. She had gotten very interested in the Ob/Gyn
47 department and related issues about health education, and also gotten very active politically.

48 Her first exposure to research ethics, she said with a reminiscent smile, came during a
49 trial studying the effectiveness of the interuterine device called the Lippes loop. Her job involved
50 recruiting women into the trial, and when she told one of the principal investigators that she
51 would like to enroll because she was looking for an effective contraceptive device, he told her
52 not to consider enrolling but to wait until they knew more about the device's safety and
53 effectiveness. Ruth said that this was "my first bioethics 'a-ha' moment," because she was
54 horrified at the thought of the information she was giving women in attempting to recruit them.
55 As a result of her work in family planning counseling and the issues it involved, she ultimately
56 decided to work in public health, particularly women's health issues, and dropped her plans to
57 get a PhD in American Civilization. She had applied to Stanford's English Literature
58 Department's Doctoral program, which was the closest she could find to American Studies, and
59 also to the MPH program at Berkeley. She was admitted to the MPH program with free tuition
60 and a \$3600 public health traineeship stipend, which was another factor in her decision as her
61 husband was still in residency training. When she began her MPH program, she saw herself as
62 working on women's health and sex education. She got involved in the founding of a group
63 called the Coalition for the Medical Rights of Women, which in part was concerned about
64 allegations of sterilization abuses among Hispanic women in southern California. "That's how I
65 got to informed consent issues, and the rest is history." It was, she said, "a great time to be at

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66 Berkeley.”

67 After receiving her MPH, she went on for a PhD at Berkeley in their Program in
68 Attitudes and Behavior. Her decision to get a PhD, she said, “was the academic part of me.” She
69 was influenced by a social psychology professor who also taught in the School of Public Health,
70 who showed her how the PhD program would tap into her interest in what later was called health
71 behavior. While in the PhD program, she and some colleagues got a DHEW grant for a nonprofit
72 group they had set up to develop educational programs for family planning. Some of these
73 materials, reflecting the time, were called “disclosure materials” for contraception, which became
74 the subject of her dissertation.

75 In doing her dissertation work on informed consent, Ruth had a series of talks with
76 David Louisell, professor of law at Boalt Hall, the UC-Berkeley School of Law. This, she said,
77 was where Al Jonsen comes in, having told me at lunch that Al had served on her dissertation
78 committee. While doing some of her early dissertation research and talking with David Louisell,
79 Ruth said she had “another crisis: I should go to law school!” When she said this to Louisell, he
80 replied, “no, not law school. All the questions you’re asking me are philosophical, not legal. You
81 should talk to this priest in San Francisco, Al Jonsen.” Louisell then called Al, and set up a
82 meeting for Ruth with him. In talking with Al, he in turn said that “the person you should really
83 be working with is Jay Katz.” Al called Jay, who said he would be glad to talk with her and read
84 her dissertation. “I was amazed,” Ruth recalled. She subsequently had a chance to go to Yale and
85 talk with Jay, and described him as “incredibly encouraging about my working on a
86 psychological theory or model of informed consent.” Another source of encouragement was Herb

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87 Kelman, the renowned Harvard psychologist, who became very involved in arguing against
88 research involving deception. Ruth recalled that when she was writing her dissertation,
89 “deception issues were breaking open.” She was on a panel that Professor Kelman also was on,
90 and “he encouraged my interest in research ethics.” Her dissertation, and Brad Gray’s
91 dissertation, which was done a couple of years before hers, were the only two dissertations using
92 empirical methods to study research ethics and consent issues.

93 After receiving her PhD from Berkeley in January 1976, Ruth was recruited by the
94 Johns Hopkins School of Public Health to teach health behavior in the field that would become
95 know as health psychology. Her husband was working at Walter Reed, so the offer from Hopkins
96 was an opportune one. Al Jonsen, when he learned she was going to Hopkins, gave her a letter of
97 introduction to André Hellegers. The Kennedy Institute had been open since 1971. Ruth recalled,
98 and “André was collecting souls.” These “souls” included Dick McCormick, who later would
99 become the Director of the Kennedy Bioethics Institute; Tom Beauchamp, who became Ruth’s
100 second husband; and Tris Engelhardt, Jim Childress, and LeRoy Walters. Ruth began working at
101 Hopkins in January 1976, and about a year and a half later André Hellegers had successfully
102 arranged with Hopkins for her to be at the Kennedy Institute one day a week, with the Institute
103 paying Hopkins 1/10th of her salary, an arrangement that has lasted to the present time.

104 END OF DICTATION, BEGINNING OF RECORDED INTERVIEW

105
106 Swazey: Tell me about starting bioethics teaching and research here at the School of Public
107 Health, because I think it still is fairly unusual in schools of public health.

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108 Faden: Because I was here, I think we probably had the first course, which I said I was going
109 to teach when Hopkins hired me.

110

111 Swazey: When we started the BU School of Public Health, we simply put ethics into the
112 curriculum, because three or four of us decided it would be interesting to teach.

113

114 Faden: I actually started at Hopkins in January '76 because my daughter was born in July
115 1975; I was supposed to start in September of '75 but I begged off til January. My
116 appointment at the Kennedy Institute was all finalized by September '78.

117

118 Swazey: How did you go about getting the Bioethics Institute started at Hopkins?

119

120 Faden: We had a program here well before we had an institute. In a large measure, I think
121 because of the Kennedy Institute, I could keep my interests in bioethics alive. Right
122 away, from the beginning, I was very fortunate because I hooked up with Tony
123 Holtzman. I always tried to find a way to look at the intersection of ethics and public
124 health policy, and our first study together, using empirical methods, looked at the
125 issue of whether PKU screening should be mandatory or voluntary. I was very lucky.
126 No matter what, wherever we were getting our money, because you have to bring in
127 your own money here, I could find an angle like that. And Tony was a great person to
128 collaborate with. We had a lot of fun.

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129 I can't remember when I taught the first course. I just declared that I wanted to teach a
130 course in ethics and public health and had some difficulty getting it through the
131 curriculum committee. It probably was about 1978, but I'd have to go back and look. I
132 had been here about 2 years before I finally got permission, like they're doing me a
133 favor to teach this course. And it was immediately extremely well received by the
134 students. We continued along for awhile and I got a colleague pretty quickly, who is
135 still here, Steve Teret, who is a lawyer. He does true health law, which is what my
136 daughter wants to do. He doesn't do bioethics. He does fire arms and tobacco policy
137 and stuff like that. Great stuff. Steve and I were weird faculty in the School of Public
138 Health. I was less weird since I could crunch numbers and Steve learned to crunch
139 numbers, learned a lot about epidemiology, but we were sort of the law and ethics
140 folks and people put us together and we were like a vaudeville team. They'd trot us
141 out, "here's law, here's ethics." Steve taught law and public health, I taught ethics and
142 public health, and we started getting students who were very engaged by this.

143 Somewhere along the line, we went to the chair of the department and then to the
144 dean, who at that point was D.A. Henderson, who was very supportive, and said we
145 want to create something and call it the Program in Law, Ethics and Health. D.A. said
146 "fine, you are now officially the Program in Law, Ethics and Health." I can't
147 remember when this was, but one of the first things we did was develop formal
148 collaborations with Georgetown. We set up a consortium arrangement with
149 Georgetown University, the Arts and Sciences side, that allowed our public health

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150 students to take courses offered by Kennedy Institute faculty in the philosophy
151 department, and allowed doctoral students in bioethics and philosophy at Georgetown
152 to take courses at the School of Public Health. The reasoning then being that the
153 philosophy department at Hopkins had no one interested in what we now call practical
154 ethics, but what we used to call applied ethics. Georgetown didn't have a school of
155 public health and had no health policy. Now they do have health policy people. So we
156 set this up and it was a big deal because it was tuition-free. The two presidents liked
157 each other -- it was Muller and Healy and they were buddies from whatever
158 university presidents' club there is. And they agreed so we set up this arrangement
159 which allowed students to take courses back and forth.

160 Then we went to the law school. Judy Areen, a friend of mine who was then an
161 Associate Dean and is now Dean of Georgetown University law center, and Steve and
162 I decided we should have a joint JD/MPH program on the law side where bioethics
163 would be the focus. We got that approved fairly early on, and the joint JD/MPH
164 program still exists.

165 Next we developed a concentration in bioethics under the Program of Law, Ethics
166 and Health so that any student in the School, if they took 4 or 5 particular courses,
167 could say it was like a minor. We started getting people who wanted to do doctoral
168 work. And so several years ago we set up a formal doctoral program, got it approved
169 through the graduate board, and a PhD in bioethics and public health, in health policy.
170 I think it's formally a PhD in health policy and bioethics. In the meantime I had two

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171 students, before there was an official doctoral program, who now have wonderful
172 careers in bioethics -- Nancy Kass and Gale Geller, both of whom are still at Hopkins.
173 They'd gotten doctoral degrees in health policy, but there was no official bioethics
174 part of it. The Program in Law, Ethics and Health became the basis for the Bioethics
175 Institute. The Program in Law, Ethics and Health was around for maybe 10 years
176 before the Bioethics Institute happened.

177

178 Swazey: You must be the only school of public health that has that PhD configuration.

179

180 Faden: Probably, and we obviously don't advertise it, which is our mistake I guess. But we
181 can't handle a lot of students, and I've never been really good at promotion.

182

183 Swazey: Mass marketing!

184

185 Faden: I'm learning now to do it.

186

187 Swazey: I've been struck by the relative absence, and a place like this is an exception, of work
188 on some of the broader ethical issues in public health. You see all the AIDS stuff, and
189 the standard epidemiological research issues of privacy, confidentiality, etc, which are
190 not unique to public health. But there doesn't seem to have developed a broader thrust
191 in areas like you were working on a long time ago, like health behavior, behavior

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192 change, etc. I'm curious as to why not.

193 Faden: I don't know why not. I think if I had just strung together all the lectures we've given
194 here, then taken that next step and turned it into a book or textbook, that would have
195 helped. Probably lots of people are kind of torn in a way. So some of it is probably
196 just unfortunate. Some of us who have been working and teaching haven't really
197 taken the next step and turned it into a text. But I think some of it has to do with
198 public health itself. And that is, as you well know, if you think about it disciplinarily,
199 you've got a huge problem because it isn't one community, it's not like medicine. All
200 right, it's true that the transplant surgeons have a different following than the
201 neonatologists, but there's something extremely foundational about being socialized
202 as a physician for which there is no analogue in public health. So if you're talking
203 about why there is no well worked out ethics of public health the way there are
204 alternative models of the ethics of clinical medicine, or something... you know,
205 "which public health?" As you point out, the epidemiologists and the people who do
206 research with essentially borrowed social science methodologies have one set of
207 concerns and issues; the people who are working in the lab have another set of issues;
208 the people who are in maternal and child health often come from 16 different
209 disciplines, and so off you go. I'm not even sure it's the right question.

210

211 Swazey: I guess I wouldn't say an ethic of public health but ethical issues in public health.

212

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213 Faden: And then I think in some areas you'd say, "well why not?"; for example, in behavior
214 change, which I used to write about but I haven't done much lately. I don't know. I
215 think it's also the way things get carved up. For example, when you look at the
216 literature on ethics and access to health care, public health could own it if they wanted
217 to claim it because where is health policy? It's more in academic programs, so you
218 could say "well actually there is a well worked out literature." It's got a long way to
219 go to be of any practical use, but when people ask where are the writings on allocation
220 and access and so on, those are health care issues; they really don't properly belong in
221 schools of medicine as much as they do in health policy units. It's just that public
222 health hasn't been good at claiming it. There are very few people who go out there
223 and waive the public health flag and say, "wait a minute, managed care is really a
224 public health issue." Or better yet, deal with whether there should be a right to health
225 care.

226
227 Swazey: What went on when you started or co-started the Bioethics Forum at the American
228 Association of Public Health? Did it go any place?

229
230 Faden: I have this memory, which I hope is right, that Gary Bauer who is now a presidential
231 candidate on the very conservative Republican side, was one of the co-founders with
232 me of the Forum. Now, either that or I dreamt it. I guess I'm having a lot of trouble
233 believing that this is really the case. But I have very vivid memories of Gary Bauer,

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234 who is very much to the right in terms of issues having to do with abortion and birth
235 control...

236

237 Swazey: I would say so! Opposites attract.

238

239 Faden: Yes, no kidding. But he was then somehow or other in public health and he was very
240 interested in ethics and values questions as he has been in whatever that family values
241 organization it is that he runs. I have to track this down because it would be kind of an
242 amusing side thing...

243

244 Swazey: Absolutely. For your true confessions.

245

246 Faden: Can you believe this? I have to go back and check it out but that's my memory. So I
247 think it was Gary and me and one other person, whose name I can't remember. I don't
248 know. I have stepped away from that. My life has gotten a bit crazy. But former
249 students of mine are very interested in the Forum on Bioethics. I rarely go to public
250 health meetings. I don't go to meetings much, period, and if I go I give my talk and
251 then I leave. But students of mine or younger colleagues who have worked with me
252 are very involved in leadership, program chairs, presidents, all this kind of stuff, as
253 well as obviously many other people, so I think it's a going concern.

254

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255 Swazey: There's only so much you can do. Do you remember roughly when you started the
256 forum?

257

258 Faden: 1978 maybe, something like that. We can dig this up somewhere. Actually I don't
259 know why I say that. We may not be able to dig it out. I think it was before 1980, but I
260 can't swear to that.

261

262 Swazey: Moving to another topic, how would you characterize bioethics?

263

264 Faden: I sometimes think about it through the sociology of a field sense because I had this
265 wonderful opportunity to sort of fall into health psychology and bioethics at about the
266 same time, and I ultimately ended up doing bioethics. You watch what happens when
267 something has a kind of start-up. I also saw it here in epidemiology; all the people
268 who did epidemiology, nobody had degrees in epidemiology, and now we give PhDs
269 in epidemiology. I think schools of public health make you think about
270 interdisciplinary fields differently, because as we discussed before it's smooshed in
271 together. Now we have doctoral programs in health services research, but all the
272 faculty have disciplinary degrees, the older faculty.

273 One way of thinking about bioethics is as an academic field that is

274 interdisciplinary. It starts out with people, none of whom obviously could be trained

275 to do what they are doing because the field doesn't exist, and then 30 years later

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276 we've got doctoral programs and we've got concentrations in PhD programs and
277 people who are within disciplines, and we've got post-doctoral fellowship training.
278 Now you've got to get trained where almost everybody who is running these
279 programs has no training, which is an interesting issue to think through. Relatedly,
280 we've got the disciplinary thing. If it's inherently interdisciplinary... I think about this
281 a lot. I worry about this a lot because of my kind of commitment and training. If it's
282 inherently an interdisciplinary field and arguably we want people to stay grounded in
283 different disciplines and then come to bioethics from a very disciplinary background,
284 then what are we doing offering programs in bioethics as such? So that's a big issue.
285 But its being interdisciplinary raises questions about whether we have any coherence
286 or integrity as one field, about how you judge scholarship, about whether one
287 discipline, like philosophy, is privileged relative to other disciplines. What does that
288 mean? And perhaps most immediately whether we're breaking out into two groups.
289 And again I'll draw the analogy to health psychology. Health psychology started out
290 much less complicated than bioethics in that it was bringing in people from different
291 branches of psychology: social psychology, clinical psychology, physiological
292 psychology, which in fact have very little to do with one another but nevertheless
293 somehow roughly all fall under the label of psychology. And for awhile there it was
294 kind of smooshed in together and then it started to divide up into two groups: there
295 were the academics who did research, and the people who started doing service stuff
296 like smoking cessation programs and other kind of interventionist service delivery

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297 working for health care provider groups and offering counseling and so on, as
298 opposed to people who were staying and getting jobs as university professors. I'm not
299 sure because I haven't been active in health psychology for about 10 years now but it
300 kind of mirrored what is true of American psychology generally. If you go to the
301 American Psychological Association for example, there are two different worlds
302 happening simultaneously: the academics and the clinical psychologists. And I think a
303 lot about whether something like a pretty big split is in the picture for bioethics. I
304 don't really know.

305
306 Swazey: So you would have basically the academic bioethicist and the clinical,
307 organizational...

308
309 Faden: Whoever they are....Well, the organizational... I don't know. They're the people who
310 are providing a service as opposed to the people who are scholars. You take teaching
311 or education, that's kind of owned by both but for me as an academic, I take teaching
312 to be the academic half of this enterprise. If you are full-time working for a hospital or
313 managed care company and you're providing clinical consultation, then that's a
314 service and it may be a very important service. I don't know because I don't train
315 people to do that and I have not been involved in the credentialing debates. But I think
316 when you go to professional meetings, you see the ASBH filled with people, most of
317 whom can't possibly have academic jobs because there aren't that many academic

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318 jobs out there, or policy jobs even, but they're doing bioethics. So I don't know. I'm
319 wondering whether in the end we'll end up with something that may be like the
320 closest thing in my experience, psychology, where there's a relationship between
321 people who are academic researchers in psychology and people who are clinical
322 psychologists or who do physiological psychology as a service.

323

324 Swazey: I was certainly struck at the ASBH meeting by the number of people doing clinical
325 bioethics, whether they were social workers, nurses, doctors....I don't know what the
326 breakdown on that was but I would have to guess they were the majority of attendees.

327

328 Faden: We would think just in terms of the jobs and the numbers and the opportunities, it
329 would have to be the clinical service area, and of course that's true in psychology as
330 well. The smaller base is the training base and people go off and provide a service;
331 it's like academic medicine and people who are in practice. There are certain people
332 who do academic medicine and there are people who practice. I don't know how
333 that's going to go in bioethics. It is a big question.

334

335 Another big question is this disciplinary issue. I hate the term bioethicist. On the
336 other hand, it's now become almost... it's just sort of around. It seems to be more
337 appropriate to say I'm a lawyer who does bioethics, or a philosopher who does
338 bioethics, or a sociologist who does bioethics, than to say "I'm a bioethicist." Though
if you're one of the service people, then you really do want to say "I'm a bioethicist."

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339 So I think we have big disciplinary issues. I also think we have real questions about
340 the quality of the work that's done with some things on the academic side. So let me
341 just step back. I don't feel really competent to speak to clinical bioethics. Fortunately
342 I have colleagues here at Hopkins who do.

343
344 Swazey: Talk more about what you see as the pros and cons of bioethics becoming a
345 discipline.

346
347 Faden: Well, it's interesting to me. I still incline to the view that it's better, both in terms of
348 self- interest and better for the field of bioethics, for people to be trained in something
349 and to have bioethics be the area they work in, which is why we've invested so
350 heavily in our Greenwall post-doctoral program. I think it's right. I have no
351 discomfort at all around the idea of offering post-doctoral training to somebody who
352 is already a fully formed something and then decides they want to do their work as a
353 lawyer or a sociologist or an economist or a theologian or physician or whomever in
354 bioethics. I think that's great. I'm comfortable with doctoral programs that have a
355 focus in something else having a big subfocus in bioethics. I'm thinking mostly of
356 philosophy departments like Georgetown or Kentucky, where the Nelsons are. You
357 have a doctoral program in philosophy and you say, "we've got some people on our
358 faculty who do a an awful lot in bioethics, if you come here, you're going to get a
359 chance to do a lot of bioethics." Fine, but you still come out with a philosophy degree.

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360 Here, what we've done is we've said, "You have to do everything that all the health
361 policy doctoral students have to do. Now, it's a issue with what health policy is; we'll
362 put that to the side. But you also pick the work that you'll do in health policy that's
363 going to be distinctively bioethics." I don't know what it means to get a degree in
364 bioethics by itself.

365
366 Swazey: One question is what would a PhD in bioethics look like if somebody starts such a
367 program. Case Western has been having an active discussion about that, and people
368 we talked to there said "we think it would be fun to do." I'm not sure how compelling
369 a reason I saw that as, but what would a PhD in bioethics be?

370
371 Faden: It goes to the core of what bioethics is, and you've got a field that has different
372 methodologies. What we emphasize here, for example, is because it's a health policy
373 program with its roots in empirical policy analysis, so the people who come out our
374 program know how to do empirical, essentially social science, work in bioethics. .
375 Our last two students have been very attracted to qualitative methods. That's what
376 they have their training in, which is great. We fortunately have the resources here to
377 allow them to do that. But I get this all the time: people will come and say, "well, I
378 don't know whether to apply to your doctoral program, I don't know whether to go to
379 law school or go to philosophy graduate school." The answer is easy. Do you want to
380 be a philosopher or a lawyer or a health policy analyst? Answer that first. You can be

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381 a leading figure, if you're talented enough, in bioethics 15 years from now from any
382 of those disciplines. Just decide first if you want to be a philosopher, a lawyer, a
383 physician, an economist, a health policy analyst. etc.. If you're interested in being a
384 health policy analyst, go to the program in the School of Public Health. If you want to
385 be a philosopher and do bioethics as a philosopher, go to the Philosophy Department.
386 If you think about epidemiology, however, nobody was an epidemiologist 50 years
387 ago. And now it's perfectly legitimate to get a PhD in epidemiology. But there's been
388 a settled sense of the methodology in epidemiology. I think that's what we don't have
389 in bioethics and we may never have. In my own work, I found it very congenial to
390 integrate essentially historical methodologies with philosophical analysis and
391 empirical research and I've been lucky to have very good collaborators who bail me
392 out when I'm weak. But by and large, you've got a field where people write the kind
393 of stuff that reflects how they've been trained. And so we don't have a bioethics
394 methodology and we may never. I don't know that it's in our future to be like
395 epidemiology, and eventually 33 years from now we can say "these are the
396 methodological tools of a bioethics person," because we are still drawing on these
397 different disciplines. You can teach method now in bioethics but it's almost all
398 strategies. It's coming from philosophy, the different moral approaches, but that's not
399 really for bioethics as much as it is looking at philosophy. We make our post-doctoral
400 students, for example, take a course that Tom teaches at Georgetown called Methods
401 in Bioethics. It's a wonderful course that looks at the disputes between principlism

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402 and feminist perspectives and casuistry. If you think for half a second, you realize that
403 these are all kind of borrowed or essentially mirrored debates from debates in moral
404 philosophy generally. I'm delighted our students have an opportunity to spend a
405 semester getting steeped in this material. But I guess if I had a short answer, I'd say I
406 think at least for a while we're going to muddle on as this kind of amalgam on the
407 academic side . So I would say, as I say all the time, "go get the best training you can
408 get. You want to be a historian working in bioethics? Go to the best place to do
409 history of medicine you can go and come do a post-doctoral fellowship with us or
410 with somebody else. It will fall into place for you. If you want to be a philosopher, get
411 into the best philosophy program you can get into. If you want to be a lawyer, go to
412 the best law school you can and then if you're really good, we'll take you into our
413 post-doctoral program or somebody else will." That doesn't sound like a recipe for a
414 kind of coherent new discipline as much a recipe for staying an interdisciplinary field.
415 You must have lots of thoughts...

416

417 Swazey: I think I very much agree with you. Some of the people I've interviewed have said
418 bioethics is now a discipline but then they really can't articulate why. Sociologically,
419 to me, it doesn't have the hallmarks of a discipline, as you've said. Some also say it's
420 a profession, but I would say it may be in the process of becoming a profession.

421

422 Faden: It may be a profession, but again, a profession is a kind of service thing, as opposed to

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423 a scholarly thing. When I think about who produces really good work in bioethics, it
424 comes from lots of different places.

425

426 Swazey: I think that's partly what is giving the field a lot of the richness it's had, from all the
427 different backgrounds. Hopefully learning to talk to each other.

428

429 Faden: The other interesting thing is all the younger people coming up who are dual-degreed.
430 This is great. You now know my story. I bumped into this person, who bumped into
431 that person, then all of a sudden I'm running a bioethics institute. But now I couldn't
432 do it that way. Now I'd have to get another degree or I'd have to do a post-doctoral
433 fellowship. And that's ok. So in that sense, there's been maturing as an
434 interdisciplinary field. But if you think about other fields that are interdisciplinary,
435 you get a PhD in biology then you go do a post-doc in neuroscience or something.

436

437 Swazey: I have a sense that now and for the foreseeable future, if there was a PhD in bioethics
438 program, it would be very heavily skewed to philosophy, because philosophy has sort
439 of been at the head of the Round Table in King Arthur's Court.

440

441 Faden: It's the privileged discipline. It's bio-*ethics*. The ethics has got to come from
442 someplace -- unless you're interested in the descriptive sense of descriptive ethics,
443 and there are more and more people doing qualitative and quantitative descriptive

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444 research, and that's important and great. I've been doing it sort of quietly. People have
445 been doing it for a long time but the cachet or the heart of bioethics has been
446 normative, which has got to come from someplace. To me that's always been like,
447 "So what? That's right." And it means that those of us who are not formally trained in
448 moral philosophy, and not all the philosophers who started out in bioethics were
449 trained in ethics either, so

450

451 Swazey: Most of the ones I've talked to said ethics wasn't taught, there weren't ethics courses
452 in their PhD in philosophy programs. Or if they got a religious degree, they didn't
453 have an ethics course in the curriculum. Some of them have said, "we had one and it
454 was so awful, I never wanted to do any more ethics."

455

456 Faden: And now they're doing bioethics! In our doctoral program, which is very tiny -- we
457 make the students take a number of philosophy courses, they then have to select a
458 string of empirical courses; they can either do a quantitative biostat and survey
459 research track or they can do minimal biostat and more qualitative methods courses.
460 And they have to take a whole bunch of health policy courses.

461

462 Swazey: They're coming out with multiple substantive knowledge bases and methodologies,
463 which I think that's what can make a person interdisciplinary and a field
464 interdisciplinary. I still draw distinctions between multi-disciplinary and inter-

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465 disciplinary. To me, interdisciplinary is really people working together and multi-
466 disciplinary tends to like most conferences, where everybody talks out of their
467 disciplinary box for three days.

468

469 Faden: Right, a lawyer gets up and sits down, an economist gets up and sits down...

470

471 Swazey: And there's no real conversation.

472

473 Faden: It's an interesting challenge. Right now...

474

475 Swazey: It's up for grabs.

476

477 Faden: I think it is. I think it's totally up for grabs. I think that those of us who train people
478 have to be very responsible and very mindful of this. I've said here many times, the
479 first time you graduate somebody who doesn't get a good job, the program closes,
480 unless there's something wrong with the person. So far it hasn't been a problem but
481 we produce very few PhDs in health policy and bioethics and they're very well
482 trained. Put aside what a health policy analyst is, there's a whole department here and
483 we train them; you can go into that market with as much confidence as everybody else
484 who comes out of here, who goes into the market and goes to work for HHS or Kaiser
485 or whoever. And the same with our post-docs. Right now, it's a very young program

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486 and our fellows are in high demand and it's been great. But we have to be mindful
487 that at some time we may have saturated the world with people who want to do work
488 in bioethics.

489
490 Swazey: Where does that put the huge proliferation of masters programs?

491
492 Faden: Well, I think this is interesting. I think that a masters program, at minimum, as I
493 believe many of them are, should be restricted to somebody who is already a
494 something else. So if it functions like our post-doc functions, then you get a masters
495 degree. I think that's fine. In fact, I think it's quite appropriate. So if someone who is
496 already a nurse, a physician, a lawyer, a social scientist of some stripe, now wants to
497 turn her work to bioethics and wants to get a post-doc or a masters, I think that's
498 great, assuming they then can have jobs in bioethics when there done . If it's to train
499 people who are going to do clinical bioethics, what John Fletcher has been interested
500 in, if I understand it right, that makes sense too. The Bioethics Institute here at
501 Hopkins started out university-wide, we cover medicine, nursing, public health, arts
502 and sciences, and immediately people started saying we have to start offering a
503 masters degree. There are now MD candidates who want an MD/MA, or PhD students
504 in philosophy who want to get an MPH or MA. I'm all right with those permutations.
505 It's like our JD/MPH. This makes sense to me. What I don't understand is what it
506 would it mean for somebody to come from undergraduate school and get a masters

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507 degree in bioethics. This makes me really nervous. I have no idea what that does for
508 anybody except maybe intellectually it could be very interesting or they go on to do
509 some more graduate work. I mean, I just don't know. I would feel very odd, worried,
510 about a program where you could go from where you just got your BA and you start
511 your MA program in bioethics. Are there any like that?

512

513 Swazey: Oh yes. From the MA programs that we've looked at, and we have descriptions of
514 almost all of them, they do have some kids coming right out of college.

515

516 Faden: What do they do when they get out?

517

518 Swazey: Most of the programs are not really good on their follow-up data about their
519 graduates, I must say. But some go on to graduate school, others are saying, "I want to
520 get a job as an administrator for an ethics committee or an IRB."

521

522 Faden: Well, I guess that's ok. As a personal matter, I wouldn't want to have anything to do
523 with a program like that, but I suppose if you were careful and made sure these people
524 had realistic expectations of whatever competencies they would have, it would be fine
525 to say you can go off to be an administrator of an IRB.

526

527 Swazey: I would be very nervous if somebody came in from college and said, "I want to get an

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528 MA and then do clinical bioethics consulting.” I’d really grit my teeth.

529

530 Faden: That’s what I’m worried about. Or if somebody gets hired by a community hospital to
531 run their bioethics consultation service. Now why am I nervous? That’s a good
532 question. I guess it goes back to the fact that I think there’s a certain background you
533 need to bring to bioethics. Maybe that says that, by itself, the field is not enough.

534

535 Swazey: I remember when I was at BU, we’d get letters from people finishing their doctorate
536 in philosophy, saying they wanted to go into bioethics and what then was sort of
537 embryonic hospital consultation. If they asked, “Do I need to know anything about
538 medicine?” those letters would just go into the waste basket. If you need to ask that,
539 we’re not even going to respond.

540

541 Faden: We have so many nurses and physicians who are interested in bioethics who are now
542 willing to invest in getting a second degree or doing a post-doctoral program, I think
543 for the clinical side of bioethics, we ought to be able to do that with people who are
544 clinicians. Medical people as well as non-medical people can constructively analyze a
545 case, and do it well. But as you get more and more people who are clinicians anyway
546 and they can do it just as well, why do they need you? And I’m being a little harsh. It
547 depends, again, if it’s a teaching context. I think it’s great that our house staff and our
548 medical students, our entire nursing and medical staff for that matter, get exposed to

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549 people who are very rigorous thinkers in bioethics who are not clinicians. I think
550 that's very important.

551

552 Swazey: It's a different way of thinking.

553

554 Faden: It is different, but if we're talking about do they need to have one of those people on
555 the hospital ethics/clinical consultation service, it would be nice but it's hardly
556 necessary. We've got some very talented people who are physicians and nurses who
557 have double degrees already that are part of our institute and they do a wonderful job.
558 They don't have to have a quick cram course in clinical medicine; they can go right to
559 it. So I don't know. It will be interesting to see.

560

561 Swazey: Yes it will be, and you wonder if at some time if there's going to be a saturation of the
562 service market.

563

564 Faden: I really don't know. I have almost no experience with community hospitals. I've spent
565 my whole life at Hopkins.

566

567 Swazey: It's interesting being in rural Maine. It gives you a different slice of the world.

568

569 Faden: I don't even know how they do it in the suburban hospitals in Montgomery County,

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570 where I live. I know how we do it here and in similar academic medical institutions,
571 but that's totally different.

572

573 Swazey: It's an ambiguous future.

574

575 Faden: It's exciting to be in bioethics.

576

577 Swazey: Let me get you to talk a little bit about one of our other major areas of interest: the
578 relationships with different disciplinary fields and how they've shifted over time. One
579 that Renée and I have obviously thought a lot about is social sciences. You and Tom
580 Murray are sort of unique in bioethics coming from social psychology.

581

582 Faden: Yes, not a whole lot of people...

583

584 Swazey: What's been your sense of receptivity of bioethics... I guess here I'm primarily talking
585 about the philosopher/bioethicist -- to the social sciences?

586

587 Faden: I actually think there are so few social scientists, and it depends on how people think
588 of other people, which is kind of interesting. Do people think of Brad Gray or Renée
589 as primarily in bioethics or primarily in something else,? as a case in point. There just
590 aren't that many of us. I don't need to tell you this. So that I don't know that there's a

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591 view. My suspicion is that it's very ad hominem. It's my suspicion that there might be
592 a view, rightly or wrongly, about physicians in bioethics or lawyers in bioethics or
593 nurses in bioethics, but I don't know that there's a view out there about social
594 scientists in bioethics because there's just not enough of us. I don't even think we're
595 viewed as a block.

596

597 Swazey: Someone like Reneé or I, who've never worked full time in bioethics, keep being
598 identified as bioethicists, as do George Annas or Alex Capron working in health law.

599

600 Faden: I hate the term bioethicist.

601

602 Swazey: I think it's probably changed some over the 30 years Renée and I have been studying
603 and participating in the field. But I think if you look at philosophy and social science
604 it's distilled from real tensions about universalistic ethical standards and social and
605 cultural variables...

606

607 Faden: Right. There, too, I don't know. There's an awful lot of interest in this, obviously in
608 the School of Public Health. On the one hand, everybody wants to be extremely
609 careful of those differences, but at the same time there's a huge commitment to
610 human rights. So immediately you get, "ok, lets start thinking about what does it
611 mean to be committed to an understanding of universal human rights," which seems

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612 sort of foundational to people in public health. We do case after case, like female
613 genital mutilation, and try to work all these sorts of things through... international
614 relief issues and things of that sort. But I see where you're going with that.

615

616 Swazey: There's been a lot of fault on both sides. Social sciences, particularly sociology which
617 is not in very good shape as a discipline...

618

619 Faden: Well, and anthropology, too. Years and years ago we did this book on ethical issues in
620 social sciences. When we were doing the book, that was clearly a tension. Now the
621 tension has come back, in some respects, in an odd almost reverse sort of way, with
622 respect to the vertical transmission and interruption trials in Africa where you've got
623 almost a flip-of allegiances and commitments. I think we may be in for a more
624 thoughtful, new territory. In that regard, one of the messages from Jonathan Mann that
625 people didn't pay enough attention to was, "Wait a second folks. There used to be this
626 big clash about respect for autonomy thing, this whole Western stuff, moral
627 imperialism, and so forth. But if you look, if there is a single factor that seems to be
628 associated with ill health and with gaps in life prospects, it's denial of dignity." He
629 was saying that in a deeper sense, if we had a more profound understanding of
630 autonomy commitments to encompass a whole treatment of a person, politically as
631 well as a more narrow construction of autonomy rights and refusing treatment, this
632 American bioethics way of looking at it, in fact it's not a tension. There used to be

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633 this view of public health on the one side and respecting autonomy on the other;
634 respecting cultural differences versus these big Western images....I think maybe we all
635 boxed ourselves into corners.

636
637 Swazey: Partly because it is such a tricky, complex set of issues. When you read the Universal
638 Declaration of Human Rights, and so forth, and then realize all the subtleties, you can
639 stay right within our country with all our cultural differences. You don't have to go to
640 Bongo-Bongo land. It's terribly complicated.

641
642 Faden: And yet you do have all of these nations, these diverse signatories to the Declaration
643 and...

644
645 Swazey: In principle.

646
647 Faden: Totally in principle, including the United States, and we didn't sign all of it. Anyway,
648 I'm thinking more along those lines. I think that we've gotten much more interested in
649 distributional and justice considerations in the American context. I also think
650 increasingly that when you peel back what at first looks like issues about "don't
651 impose Western informed consent on us," there are very important underlying
652 questions about dignity and political equality that we haven't begun to deal with in
653 bioethics, that may actually cause us to have less of this tension between

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654 universalism and social and cultural differences.

655

656 Swazey: Has bioethics grown up enough to start doing that peeling away?

657

658 Faden: I hope so. At least a few people will start and then more people will start, and we'll
659 see. I don't really know. I think there's not nearly as much interest, in some respects,
660 in profound questions about international injustice as they relate to questions of
661 health, as I would like there to be. We try to focus on it in the School of Public Health
662 part of our Bioethics Institute. There is another part of the Bioethics Institute which
663 focuses on the new biology. That's important and it's absolutely fascinating. But
664 there's not enough talent in bioethics, and the talent is attracted to an area like
665 genetics for good reasons.

666

667 Swazey: The genome project has been the bioethicist relief act in terms of grant money.

668

669 Faden: That's basically where I was going. They are important issues, and I do find them
670 engaging. But if the talent goes there to the extent that all the interesting thinkers are
671 engaged by these important issues, these other very important issues like human rights
672 won't get as much attention...it's like in any other field.

673

674 Swazey: Well it is, but it seems to me that the genome-type issues are interesting and important

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675 at a much more micro-level. I'm not trying to trivialize it, but if you think of the
676 international...the human rights...

677

678 Faden: It's a luxury of the developed world to be worrying about the new biology right now.
679 When I work with some of my colleagues here who are trying to figure out how to
680 allocate a per capita dollar health budget that you can count on one hand, they're not
681 exactly worrying about what to do with stem cells. But on the other hand, a leading
682 stem cell researcher is here and he is a wonderful person and he's really trying to
683 think through what he's doing. You know, I support him too. It's great that he's really
684 focused on these questions and wants to talk to people who are trained in law and
685 philosophy and the social sciences about the meaning of his work and help him think.
686 So it's not that I think the issues that are coming out of new biology or genetics are
687 silly or anything.

688

689 Swazey: It's also hard to find any new ones, having been looking at those issues for 30-odd
690 years. The genome project, to me, hasn't raised new issues; they've accelerated, some
691 of them are enhanced, but not new.

692

693 Faden: You know, it's interesting that you say that. That's also, to a large extent, my view
694 too. It's amazing because especially reporters seem shocked by this. They want to find
695 the bioethics person who's going to say "this is it, this is the ultimate clash that we've

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696 all said was coming between religion and science.” I don’t think so; maybe I’m
697 missing something.

698

699 Swazey: One thing I’ve often rued historically is the way public health and medicine split up,
700 and I think that may be one factor in the disconnect between bioethics and public
701 health and also bioethics and human rights. Public health and medicine really became
702 different domains and it’s puzzling in many ways that they haven’t intersected.

703

704 Faden: Well, you’ve got George Annas and Larry Gostin and you did have Jonathan Mann.
705 George and Larry are much more identified with bioethics. Jonathan wasn’t but he
706 was determined to make the connection. But you’re right, human rights so far as it’s
707 been in the academy has been dominated by lawyers. Thankfully they’ve pursued these
708 questions while bioethics went in a different direction. There are a few programs; we
709 have one in human rights and public health here.

710

711 Swazey: Public health and human rights are connections you hope people in bioethics are
712 going to say, “why haven’t we done this?”

713

714 Faden: They will say it.

715

716 Swazey: Let’s go back to the social sciences....

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717 Faden: I'm still thinking about that question.

718

719 Swazey: Tom Murray, for example, thinks there has been much more of a rapprochement in
720 recent years. He said to me, "you've got to remember you and Renée were there when
721 everything was at it's worst and you were defined as bioethics bashers." Dan
722 Callahan, for example, offered to publish the first half of our "Medical Morality is
723 Not Bioethics" paper which dealt with our observations in China if we dropped the
724 second half which commented on the U.S.

725

726 Faden: I didn't know that!

727

728 Swazey: So those were rougher times, but then I read something like a course description in a
729 masters in bioethics program, and one of their modules is described as dealing with
730 "the universalistic ethic (objectivism)" and "social and cultural factors
731 (subjectivism)," and I wonder if we've really progressed.

732

733 Faden: I just thought we were borrowing labels from the way in which philosophers set it up.

734

735 Swazey: Yes, but to me that's troubling in terms of what students are being taught.

736

737 Faden: I was just thinking about it. I was thinking about you and Renée vs Tom and I. I bet a

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738 lot of people are clueless as to what Tom and I are trained as.

739

740 Swazey: Probably because you're totally identified as bioethicists.

741

742 Faden: Totally, and if they do know about our training they're sort of surprised. There's a
743 difference between doing empirical work in bioethics and doing research about
744 bioethics. Much of what you and Renée have done, including right now, is do
745 research *about* bioethics as opposed to research *in* bioethics. So even when I've been
746 doing my empirical research I am doing research in bioethics. One thing that does
747 worry me a little bit is physicians have found a niche in bioethics in which to turn out
748 empirical studies, because it helps with the academic medical career and publishing in
749 the right places. But there is I think sometimes a naive sort of failure to appreciate that
750 there is a good way and a bad way to do empirical social science and you need a little
751 training or at least a good colleague.

752

753 Swazey: Although it's interesting that when we did all those years of work on transplantation
754 and artificial organs, those were primarily sociological studies. We were looking at
755 some of the ethical issues that arose for transplanters and their teams in that context.
756 And that in a way has really been redefined as seminal bioethical studies.

757

758 Faden: Oh yes, because that's the empirical research *in* bioethics, which doesn't sort of make

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759 you...

760

761 Swazey: ...suspect.

762

763 Faden: ...scary, like you are if you're doing a study *of* bioethics, whereas in transplantation
764 you're doing essentially good descriptive work. It's helping to illuminate. That kind
765 of research is received wonderfully by just about everybody.

766

767 Swazey: That's when we started being defined as bioethicists.

768

769 Faden: Sure. I'm curious, how many women are you interviewing? How many women are
770 there out there to interview?

771

772 Swazey: Not a huge number. We're focusing on people who have "reputations in the field,"
773 and it's a small number of women.

774

775 Faden: That's going to change, and I suppose it's not a big shock in terms of academic life
776 generally.

777

778 Swazey: It's a male Caucasian world.

779

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780 Faden: I notice in our post-doc program, so many women are applying and they're so
781 incredibly talented.

782

783 Swazey: That's great.

784

785 Faden: It is, to the point where it's just overwhelming. You see it in medical schools and law
786 schools, everybody is seeing the change.

787

788 Swazey: Let me shift to bioethics and public policy. You've obviously been involved, apart
789 from ACHRE, in a lot of national advisory committees and so forth. How much
790 influence has bioethics had on public policy?

791

792 Faden: I don't really think I can answer that question like that. I have thought a fair amount
793 about it. I think bioethics and public policy doesn't mean a whole lot unless you start
794 taking it apart in several different dimensions. First, there are different kinds of issues.
795 There are some issues that the world has shaped as paradigmatically biomedical ethics
796 issues. Research involving human subjects, cloning, physician assisted suicide -- these
797 are issues the public perceives as bioethics issues. If you looked at those issues, I
798 think you would see a very significant impact on public policy of people trained in
799 bioethics or the field of bioethics, however you want to cut it up. And that's the
800 history of the commissions, too. If you look at the history of the President's

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801 Commission, and here I'm looking from the outside, we've got all these different
802 analyses that I think reinforce the view that where they stuck with paradigmatically
803 bioethics issues like definition of death, the Commission had a profound impact on
804 public policy. By contrast, access to care fell into a black hole. And that's the other
805 side. Lots of other issues in public policy are very socially complex and have very
806 important dimensions to them. I might think or you might think of them as bioethics
807 issues, but the public does not construct them that way. So for example, we might set
808 up access to health care as a bioethics issue, but the public and Congress do not
809 think of it that way. And there, the impact is less.

810

811 Swazey: On the President's Commission there was huge debate among commissioners and
812 staff as to whether access was an appropriate topic.

813

814 Faden: For a lot of the same reasons.

815

816 Swazey: But who's the public that you're talking about?

817

818 Faden: I don't know -- whoever we talk about. The American public doesn't sit there
819 demanding to know what "bioethicists" think. Reporters don't run around calling
820 people in bioethics when there's a debate whether to change the age of eligibility for
821 Medicare, which I thought was a very important bioethics issue. They call health

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822 economists, they call AARP. But if it's an issue of whether or not to take hearts from
823 cadavers who are defined as this, that, or the other way, or whether or not we should
824 have physician assisted suicide, or whether we should have infertility treatments, they
825 call "bioethicists."

826

827 Swazey: They call George Annas and Art Caplan.

828

829 Faden: Right. Exactly. These are perceived, and the media helps shape this, as bioethics
830 issues. So if you have a bioethics topic, then I think you can trace out and show that
831 bioethics commissions, bioethics personalities, writings in scholarship even, have an
832 impact on public policy, laws and regulations. But if you think about lots of other
833 arenas where we might say, "hey, this is an important bioethics issue," you don't see
834 the influence. And sometimes you see failed attempts. So that's one way to slice it.
835 Another way to slice it is the public policy context. We sit and write as if bioethics
836 and public policy and the history of bioethics commissions are isomorphic -- that's it,
837 that's all there is to it. But indeed you can look at what's the history of bioethics in
838 terms of its influence or impact on legislation on Capitol Hill? And there it's very
839 different. If you look at that same history with respect to state capitols -- where or to
840 what extent has bioethics or people in bioethics had an influence in terms of state law
841 or state regulatory action, it's changing. In fact it's increasing. You've got people in
842 bioethics now inside. You've got an inside - HHS, you've got them as staffers on the

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843 Hill. This is a whole new thing for us and I don't know what's going to happen. As
844 we get more infiltrated, this is the other side, you've got one movement which is
845 people in bioethics as clinical service people, and now you do have people who are
846 trained in bioethics who are starting to work for...

847

848 Swazey: Policy works.

849

850 Faden: ...policy works. They're going this other way. We don't know what's going to happen
851 with that but it can open up other possibilities for ways in which there might be direct
852 lines of influence. So I'm kind of open and a little bit hopeful, actually. But I do think
853 that we need to think about where we've had an impact. If success is defined as sort
854 of conscious effects, you can trace out where thinking in bioethics or debate in
855 bioethics has really traced its way through public policy; you can certainly see it in
856 paradigmatic bioethics issues. Refusal of treatment cases, that whole line of judicial
857 cases, can trace this out. There's a very kind of deep connection with legal cases; the
858 scholarship in bioethics is like a revolving door, and you see it with physician assisted
859 suicide as an extension of that. Research in human subjects, and now cloning, stem
860 cell research...

861

862 Swazey: It's interesting with the treatment decision cases; you really have to draw it out by
863 inference or talking to people because, quite appropriately, in court cases they don't

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864 cite the bioethics literature.

865

866 Faden: Occasionally they have.

867

868 Swazey: Very rarely. What they mostly cite in Cruzan, etc. is the President's Commission
869 defining death report, over and over and over.

870

871 Faden: And that's huge. Alex and his colleagues should rightly be very proud of that. It's an
872 overwhelming contribution. That's what I mean. You take a paradigmatic bioethics
873 issue, and bioethics really has an impact on a huge part of public policy. In contrast, if
874 you take something like the Clinton Health Care Task Force, and it was lost in a
875 disaster, but it was not an issue that was framed in bioethics terms.

876

877 Swazey: That's right.

878

879 Faden: The human radiation experiments' advisory committee is, I think, a case in point
880 where it worked. It was a bioethics issue. But it was also not just a bioethics issue, as
881 I've written. I didn't get it right away that the Administration saw this as much as a
882 kind of Cold War openness, trust-in-government commission as it did a bioethics
883 commission, like a Challenger or Three Mile Island type commission, and almost
884 maybe secondarily as a bioethics commission. It depended on where you were in the

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885 Administration how you saw it. HHS saw it, obviously, as a bioethics commission.
886 The Energy Department, I think, saw it from a kind of Cold War/truth commission
887 point of view. But it worked in part because it was the right kind of issue. If we had
888 been given something else, it could have just fallen right through...

889

890 Swazey: You all turned out such an incredible report. It's so rich and there is so much in it in a
891 relatively short period of time. That really did incorporate all the various
892 methodologies that should be used in bioethics. It's almost a model...

893

894 Faden: Thank you. We struggled with that and we were lucky. We had philosophers,
895 historians, lawyers, social scientists, we had a wonderful opportunity to do it as close
896 as we could to right. It was hard because of the time pressure. People ask me all the
897 time, "how do you situate it relative to the President's Commission...?" And
898 sometimes, what look like negatives turn out to be positives. One big negative I
899 thought initially was the fact that we had so little time. But in fact, it concentrates you.
900 You don't have a lot of choice. You know you have a very short amount of time to
901 think through the issues. When I've talked to people on some of the other
902 commissions, it took them months, sometimes years to get organized and figure out
903 what they were even going to write about.

904

905 Swazey: You didn't have that luxury.

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906 Faden: No. We had what I thought was a another negative, and NBAC has this now too: we
907 were the focus of media scrutiny and media attention from the beginning because we
908 were born out of controversy and we were going to find out deep, dark secrets. It was
909 interesting right from the beginning and I thought, “how are we...” Jay Katz, by the
910 way was really overwhelmed by the fact that we could never have a private
911 conversation, how were we ever going to come to anything. Well, it turned out to be a
912 great plus. So these sorts of negatives of the short amount of time and the intense
913 public scrutiny gave us power. To me personally, one of the things I learned about
914 was how you can get power, how you can be given power, how you can use it, which
915 was new to me. But all of those things gave us a lot of visibility and independence,
916 and we were able to do a lot.

917
918 Swazey: I really hope that people teaching bioethics methodology courses, if such exists, use
919 ACHRE’s work as a model of bringing the disciplines together in a really
920 interdisciplinary way.

921
922 Faden: Thank you again. We were lucky. We laugh sometimes, but we had such a large staff
923 who put it together so quickly. We really benefitted from the fact that there was a bad
924 job market for historians and philosophers. So we had all these wonderfully talented
925 historians and lawyers and philosophy types.

926 Swazey: What a training and experience ground for them.

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927 Faden: It was great all the way around. It was a wonderful opportunity and we were very
928 lucky in terms of who we got to deal with in the Administration. There are a lot of
929 unsung heroes here. D.A. Henderson was Shalala's HHS point person and to my good
930 luck, he's been my dean for all these years. Tara O'Toole really is the unsung hero.
931 She was the Assistant Secretary for Health at the Department of Energy, who happens
932 now to be at the School of Public Health at Hopkins. That's where she went after she
933 left government. Phil Caplan, who is the only person still at the White House.
934 Christine Varney, who left to be a federal trade commissioner, was Phil's boss at the
935 time. These are just really fine, talented people with tremendous integrity and
936 commitment. They didn't always agree with what we did but they never made it hard
937 for us to do it. But have we had an impact? I'll let other people... I'll let you answer
938 that.

939
940 Swazey: To be answered... Let me ask one more question.

941
942 Faden: Go ahead, this is a treat. This is probably the most fun afternoon I've had in a long
943 time. Don't people tell you that all the time?

944
945 Swazey: Yes, many do, actually. Most people say they were nervous about it but they enjoyed
946 it. Talk to me a little bit about what you see as the generations in bioethics.

947

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948 Faden: A generation in real life is 20 years or something like that. An academic generation is
949 clearly shorter but the idea is your first PhD.... It's easier for me to think in PhD terms
950 because I don't know how you do it if you're in law or medicine or something like
951 that. If you're a PhD, then the first person for whom you are a dissertation director,
952 that's getting into the next generation. And then they go on and eventually they have
953 their first PhD graduate and so on. So thinking about it that way, I think we're in the
954 fourth generation already in bioethics, at least in my case. Arguably, if AI was on my
955 committee and then we traced this out, there's Nancy Kass, Gale Geller, Jeff Kahn,
956 and Jeremy Sugarman, people I've helped trained and now they're all academics with
957 faculty jobs and they've got their own graduate students, I think we're sort of into a
958 fourth generation.

959
960 Swazey: So people you helped train are the third.

961
962 Faden: Yes, and now they're all academics and some of them have students who are finished.
963 One kind or another, whether they're PhD students, or MD/MA students, or whatever
964 they are. So these are very young people who are finishing now, this fourth
965 generation. I don't know where I fit. You guys will have to figure this out.

966
967 Swazey: I'm not sure how useful it's going to be but it's interesting to play with just in terms
968 of social circles and who interacted with whom. You clearly had very important

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969 interactions with André and Al and Jay that shaped your development.

970

971 Faden: And they were probably younger than I am now. I thought of them as really senior
972 “old” people, but this was 25 years ago... Al was probably in his early 40's-- younger
973 than I am now! But the field was so young, there wasn't even a field yet. I didn't go to
974 him and say, “I want to be a bioethicist” because nobody would have said that in
975 1973. We just wanted to examine these questions, raise these issues. So he was 40
976 and I was 23 or 24 and Jay was probably about 42. Tom Beauchamp and Jim
977 Childress were in their 30's. Art Caplan is probably my age. Alan Buchanan, and Tom
978 Murray too. I don't know how you sort everybody out but I think there was this big
979 blitz of talent in the beginning; André and Dan Callahan. And all these people coming
980 up close behind. Watching that transition, I think you're doing your study at just the
981 right time because, with the exception, unfortunately of André, we haven't lost
982 anybody. Well, we have, Paul Ramsey....

983

984 Swazey: Where do you put Paul and Dick McCormick and Joe Fletcher?

985

986 Faden: Joe Fletcher and Paul Ramsey would be arguably kind of harbingers -- they're sort of
987 ahead of the whole phenomenon. I guess I should look at Al's book to see how Al set
988 this up, that would be kind of interesting. Their impact was huge but almost all by
989 itself is sort of how I see it. They overlap for not that long with what then turns into

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990 this whole phenomenon. Their role is overwhelmingly important but death takes
991 them.

992

993 Swazey: Except for Dick.

994

995 Faden: Dick is interesting because he continued right up on in there. You're right, he's still...
996 he's receded a bit but when he was at the Kennedy Institute he was such a very
997 important figure and he ran the Institute for a while. And of course they're all
998 theologians. I don't know what's going to be made out of that, but I think for
999 interesting reasons people sort of kick this stuff off...

1000

1001 Swazey: One of the things we're finding the hardest to disentangle -- we've made strides, but it
1002 is so complicated -- are the roles of religious traditions in bioethics. You can say Joe
1003 and Paul and Dick had huge influences then you start asking people how enduring
1004 those influences have been. People say it tended to go away. But I think my sense is
1005 religion didn't go away, it sort of went underground. Partly because in our society it's
1006 hard not to speak in a secular voice and have large groups pay attention.

1007 Faden: It will be interesting to see what you hear when you talk to people at the Kennedy
1008 Institute, because I grew up there. For a while we had Isaac Frank who was the Jewish
1009 scholar and a very dear friend, and now Dan Sulmasy, who is sort of the young
1010 generation, who has left Georgetown but got his PhD there, as well as training with us

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1011 at Hopkins. In a way you had these people who started... then it got the Catholic
1012 medical ethics, the Jewish medical ethics, Islamic medical ethics. It's become kind of
1013 appropriate and right...it's a little rough on Protestant because we don't really know
1014 what Protestant medical ethics is; it's like Protestant theology generally, it's not very
1015 prescriptive in the way you would have it for Jewish, Islamic or Catholic.

1016

1017 Swazey: Ron Carson describes himself now as an ethnic Christian.

1018

1019 Faden: Ethnic Christian? That's a riot. I think religion kind of got to the side. Maybe one
1020 image is going underground but the way I imagine it is marginalized. You do
1021 mainstream bioethics, then there's Catholic medical ethics, Jewish medical ethics, and
1022 Islamic medical ethics. And if you're being very sensitive and it's a contested issue,
1023 you want to make sure you get all those points of view. But that's different from
1024 recognizing the powerful role of religion in people's moral commitments.

1025

1026 Swazey: I think as you talk to people in Jewish medical ethics or Judaic studies more generally,
1027 they'd be the first to say Jewish medical ethicist primarily talk to their own faith
1028 communities whether they are traditional or conservative, whereas in the early days
1029 Dick and Paul were mainstream voices in bioethics.

1030

1031 Faden: They were speaking to the whole community.

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1032 Swazey: If you read Jim Childress as Jim Childress on the RDNA advisory committee or
1033 whatever policy role he's played. and read some of the early Jim Childress when he
1034 was studying with Jim Gustafson, I think he's writing in two very different voices.

1035

1036 Faden: Right. The religious scholar and the public policy voice.

1037

1038 Swazey: We've talked to some people in bioethics who say that when they write for religious
1039 ethics journals or they're working on books, in what they define as religious bioethics
1040 framework, they do that at home at their kitchen table or their dining room table or in
1041 their study on weekends. They have a sense that it would not be viewed as an
1042 appropriate thing to do at their academic home. And that's very interesting.

1043

1044 Faden: That's kind of sad. That's actually one of the advantages of the Kennedy Institute
1045 because it is a Catholic University and because it struggles with the opposite problem.
1046 I was just thinking, how many people who are casually claiming to do bioethics,
1047 would know that Jim or LeRoy or Bob or many others come from training in
1048 theological ethics. Probably almost nobody. If you know, you're probably a little more
1049 invested in the field. But you can't tell from their writings; they're not written with
1050 the voice of a moral theologian. That's not how they're doing their bioethics. The
1051 next question is to ask them why that is.

1052

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1053 Swazey: We're looking forward to talking to Jim Childress about this.

1054

1055 Faden: Jim is a remarkable person.

1056

1057 Swazey: We're also going to spend a couple of days with Jim Gustafson in June out in
1058 Albuquerque. It's going to be a special thrill because what a man he is.

1059

1060 Faden: I never got to know him. I've only heard extraordinary things about him. I think one
1061 of the things to say about bioethics, and I don't mean to be real pollyanna-ish here, is
1062 that we've had some extraordinary... We haven't talked about Dan or Will Gaylin.
1063 There have been some really extraordinary personalities.

1064

1065 Swazey: That's right.

1066

1067 Faden: Very talented people, far sighted, like André. I really was serious. I think it takes
1068 extraordinary courage to do what you did when you said, "ok, I want to live here in
1069 Maine and I'm going to start an institute and it's going to happen." I think often, now
1070 that I'm running this bioethics institute in this big, mammoth academic complex,
1071 "how did Dan and André do this?" André in an academic context. Dan and Will at
1072 Will's swimming pool or whatever... How do you get the courage and conviction to
1073 do this?

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1074 Swazey: And they were almost ahead of the wave.

1075

1076 Faden: It's just really remarkable and I don't know enough about how other areas of study get
1077 started, but to me, so much of life seems to be about luck and personalities.

1078

1079 Swazey: You have made a lot of your own luck. You attributed a lot in your career to luck and
1080 that's too modest.

1081

1082 Faden: But it is the case.

1083 Swazey: Don't forget what Louis Pasteur said, ok?

1084

1085 Faden: Ok, fair enough, but I think we do have some very remarkable people who were
1086 around early on and that helped me a great deal.

1087

1088 END OF INTERVIEW