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Dr. Robert Levine, Yale University Dr. John Irwin, University of California

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1	Friday March 12, 1976 <u>P R O C E E D I N G</u>
2	DR. RYAN: Good morning.
3	and I would like to review with you
4	call to your attention some things t
5	your books. This morning we are goi
6	half-hour sessions a draft summary r
7	Minority Conference, a report from t
8	a preliminary report from Dr. Tannen
9	prison research . Then I hope the C
10	go on from that to deliberation on t
11	I would like to call to yo
12	book 16-A, and under Tab 6 there are
13	One is from the Pharmaceutical Manuf
14	viding for us what they said they wo
15	some limitations, of course, on the
16	going on in prisons, Phase I testing
17	pharmaceutical industry. On page 4
18	esting line up of the type of prison
19	and you will see that they are large
20	there is one city there.
21	The other item which is of
22	the correspondence back and forth be
23	man Quie, and I am going to ask for
24	

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We have a full schedule, a our projected agenda and that are of interest in oing to try to divide in report from the National the BU School of Law, and enbaum on the IRS surveys in Commission will be able to the prison research issue. Your attention Tab 6 in your e some interesting letters. facturers Association proould try to provide, with

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extent of research that is g and so on involving the

of that report, an interns that are used appears, ely state, some county, and

The other item which is of interest under Tab 6 is the correspondence back and forth between Dr. Lowe and Congressman Quie, and I am going to ask for the Commission's desires with respect to this. You have all received the letter from Mrs. Leo Kaysac (?), and Bob Cook's letter, and we may have

some -- no? I thought that they were sent to everyone. 2 SPEAKER: I received them. 3 DR. RYAN: Karen, for some reason Mrs. Kaysac didn't 4 get you on her mailing list. She got everyone else. I just 5 assumed that she had sent one to everyone. 6 Also under Tab 6 in correspondence is a letter from 7 LARASA (?) with respect to the minority caucus at the minority 8 conference in response to the letter which we sent. 9 Under Tab 7 there are some very important and inter-10 esting items, the most important being -- you have to go through 11 the first four or five pages -- the news clips, but more im-12 portant than that, Norman Crossan's directive with respect to 13 research in federal prisons, and following that, the task force 14 on medical research and their report. This is under Tab 7 --15 the task force on medical research on which he supposedly based his decision. I think that that ought to be required reading 16 17 sometime before we get too far into our deliberations on prison 18 research. Finally, there is some information from ERDA on the 19 background information on testicular radiation in the State of 20 Oregon and Washington prisons. 21 The final item under Tab 7 is President Ford's

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22 directive with respect to foreign intelligence activities.
23 That is that they would be required if they engage in any kind
24 of biomedical behavioral research to follow guidelines finally
25 established by this Commission.

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1 Have I left anything out? In any case, all that ma-2 terial is there for you to review. 3 Finally, the one other bit of reading material, if 4 you don't have enough already, is an interesting article called "Ethical Issues in Behavior Modification," by Stephanie Stolz. 5 6 With that to sort of give you your homework for the 7 first night, I wonder if we could call on the National Urban 8 group, who are meeting with us today, to give us a preliminary 9 report? David Brown and Geraldine Brooks. Would you join us 10 at the table, please? 11 MS. BROOKS: Yes. I would like to request that Mr. 12 Irv Joiner, who is Director of the Commission for Racial Justice and was a workshop leader on prisons, join us at the table 13 14 to respond to any questions. 15 DR. RYAN: Could you repeat his name, please? 16 MS. BROOKS: Mr. Irv Joiner, I-r-v J-o-i-n-e-r, 17 Director of the Commission of Racial Justice of the United Church of Christ in New York, who also was at the conference 18 19 as a prison workshop moderator and certainly contributed to 20 the development of the prison report. 21 DR. RYAN: Thank you. Please. 22 MR. BROWN: I will turn this right over to Mr. Joiner 23 for the substance of the report, and then Gerry, if you 24 have any comments afterwards, I think that would be appropriate, 25 and then we would be prepared to respond to questions.

1 MS. BROOKS: I would like to understand clearly, 2 though. Are you requesting that we speak to the draft of the 3 summary report, the total summary report, or just the one on prisons? 5 DR. RYAN: I think that the one thing the Commission 6 is most interested in for its deliberations over this week-end 7 is the summary on the prisons, and we would want to cover that 8 in any case. Whatever other information you can give us -- I 9 realize that the time is short. We will have opportunity for 10 other interchange. 11 MR. JOINER: First of all, I just want to say good 12 morning. We are out here in the wilderness. 13 DR. RYAN: Excuse me. I don't know whether it is 14 just my hearing, but could you speak a little louder? The 15 table is long and the acoustics are not too good in the room. 16 That is not a microphone; that is just for the tape recording. 17 MR. JOINER: Excuse me. I usually start low and 18 usually end up kind of high, so at some point you will reach 19 a proper level. We have -- I think the Commission needs to be 20 commended for taking the initiative to spur the development of 21 the organization of the Minority Conference on Human Experi-22 mentation, in conjunction with the Urban Coalition. I think it is a subject area that minority people have not addressed 24 themselves to in the type of deliberation that we did in Vir-25 ginia, that we need to do. As a workshop leader, one of the

sessions I was able to see a whole host of ideas and interplay going on as related to this topic. I guess our debate really ranged from those persons that wanted to halt all experimentation on prisoners, of any nature, whether it was therapeutic 5 or non-therapeutic, to those persons who were interested in 6 developing some guidelines to determine what the form was that that experimentation ought to take. 8 I think a consensus view out of that came in the form of the proposal that at a minimum, that there be a mora-10 torium on experimentation on prisoners until such time as this 11 Commission and other people are able to more fully and completely 12 discern just what is happening. There is a lot of conflict in 13 prisons as to whether experimentation ought to take place or 14 not. Some people allude to the fact to say that prisoners 15 should not be experimented on, that this is to disallow free-16 dom of choice on their part, one of the few freedoms that they 17 have, which to me does not make any sense. To give the pri-18 soner the only choice that he can make in his whole life, at 19 least for 2 or 3 weeks, the option of choosing to be a guinea 20 pig or not, is not a choice, especially when you begin to 21 dangle a lot of pretty incentives in front of him. 22 But I think that that population needs to be heard, 23 that that population needs to be prodded as to what they really 24 mean, what they are really talking about. We need to find out 25 if, in fact, the money and the coerciveness of the institution

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¹ is a factor leading to prisoners volunteering to be experi-² mented on, or whether the claims of other prisoners that this ³ is a degrading and dehumanizing activity and ought to be halted ⁴ is, in fact, the case.

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5 Outside and above the legal questions that are raised 6 in terms of informed consent, I think there is the moral con-7 sideration that we need to deal with, the moral question, what 8 is the policy statement that this country needs to make as it 9 relates to human experimentation. That goes above whether a 10 prisoner, as such, wants to be experimented on, above whether 11 a prisoner wants to give his body to society or to medicine or 12 to the local drug companies that happen to catch his fancy at 13 that point. I think this Commission has a responsibility of 14 developing in part that policy that this country is going to 15push in regard to prison populations. The ingredients of 16 that policy I think would have to be discerned from a number 17 of interests. There are definite interests that are opposed 18 to it, and there are some that are for it, and where is the 19 median ground? The drug industry, of course, is interested in 20 the cheap or inexpensive patient or subject. Some prisoners 21 are interested in the money. Some prisoners are interested in 22 trying to gain the favor of parole boards or whatever the case 23 may be. Some are just interested in trying to break up the boredom of the institutional life that presently exists.

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In looking at and trying to develop that policy,

then what factors do the oppressive conditions that minority people find themselves in play in that, and what role does this 2 Commission take in regard to formulating some type of approach 3 to how the government ought to deal with some of the underlying 4 causes of people being in prisons in the first place? I think 5 that is part of the role of the Commission and part of the - 6 thing that we attempted to grapple with in Virginia. Maybe we 7 did not do it as in depth as we should have done or we would 8 9 have liked to have done.

10 I think that most people that, for instance, appeared in my workshop were of the opinion that we need to get together 11 again to talk more about the subject after we have had an op-12 portunity to do some more studying, and also to look at this 13 whole subject relative to other minority groups, because we 14 were very heavily populated with Blacks. The Asian community 15 had some concerns, the native American community had some con-16 cerns, the Spanish speaking community had some concerns that 17 I don't think were adequately addressed at the conference in 18 Virginia. I would recommend the reconvening or the convening 19 of another conference of this type so that we can get a more 20 representative picture of what minorities are talking about 21 22 relative to experimentation. 23 DR. RYAN: Your report and recommendations are under Workshop 8 in the report. This is book 16-B for the Commission 24 members, and I don't know if you each have it in front of you. 25

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	1	It is about it is under Tab 18? It is under my Tab 18, but			¹ included
	2	I was just looking at the workshop recommendations. Tab 19.			2 main rea
	3	MS. BROOKS: I would like to call the attention of			3 two days
	4	the commissioners to page 6 of this report.		4	hours of
	5	DR. RYAN: Under Tab 19?		5	very ser
	6	MS. BROOKS: I don't have the same books you do; I		ć	group of
	7	have the report.		7	had somet
	8	DR. RYAN: All right, fine.		8	to get th
	9	MS. BROOKS: The prison report is a short report.		9	the best
	10	SPEAKER: It is Tab 19.		10	
	11	MS. BROOKS: Under Tab 19 in your books. I would		11	that he w
	12	like to refer you to page 6, and suggest to you, and for the		12	the Commi
	13	audience who may not have the report, that an examination of		13	the recom
	14	the recommendations on the use of prisoners would initially		14	ask. Dr.
	15	appear to be contradictory. For example, an item recommending		15	
	16	a complete ban on all research may be in juxtaposition with		16	torium, wł
	17	the recommendation to establish a permanent commission to		17	Would it h
	18	evaluate and monitor prison research. I would like to point out		18	would comm
	19	that the method that was used for developing the recommendations		19	of existin
	20	at the conference was one which did not require a democratic		20	
	21	vote, but merely a contributing of everybody in the workshop,		21	with did n
hany	22	so that if a person over here felt very strongly that all pri-	Сотрали	22	with those
ting Co	23	son research should be banned, and a person next to him felt		- <u>-</u>	they ought
Bowers Reporting Company	24	that maybe, to be realistic, it is not going to all be banned	rs Reporting	24	other reas
BOWe	25	and it should be continued under such conditions, that was	BOWERS	25	to continue

very serious issues, and of that time, if you had a workshop group of 20 or 25 articulate, intelligent people who certainly had something to say about it, it was very, very difficult to get that orchestration going. So these reports reflect the best effort that could be made under those circumstances. DR. RYAN: Perhaps, unless Mr. Brown has anything that he wants to add at this time, we should turn it over to the Commission members if they want any elaboration of any of the recommendations or have any questions that they want to ask. Dr. Louisell.

DR. LOUISELL: Under the recommendation for a moratorium, what would be the plan as to existing research projects? Would it be that they could be completed and then the moratorium would commence, or would you contemplate an immediate cessation of existing projects?

MR. JOINER: The workshop participants that I met with did not get into what would happen or what should happen with those projects presently under way. I would think that they ought to stop. Other people, for economic reasons and other reasons, would say that for practical reasons they ought to continue until their completion, depending on the stage

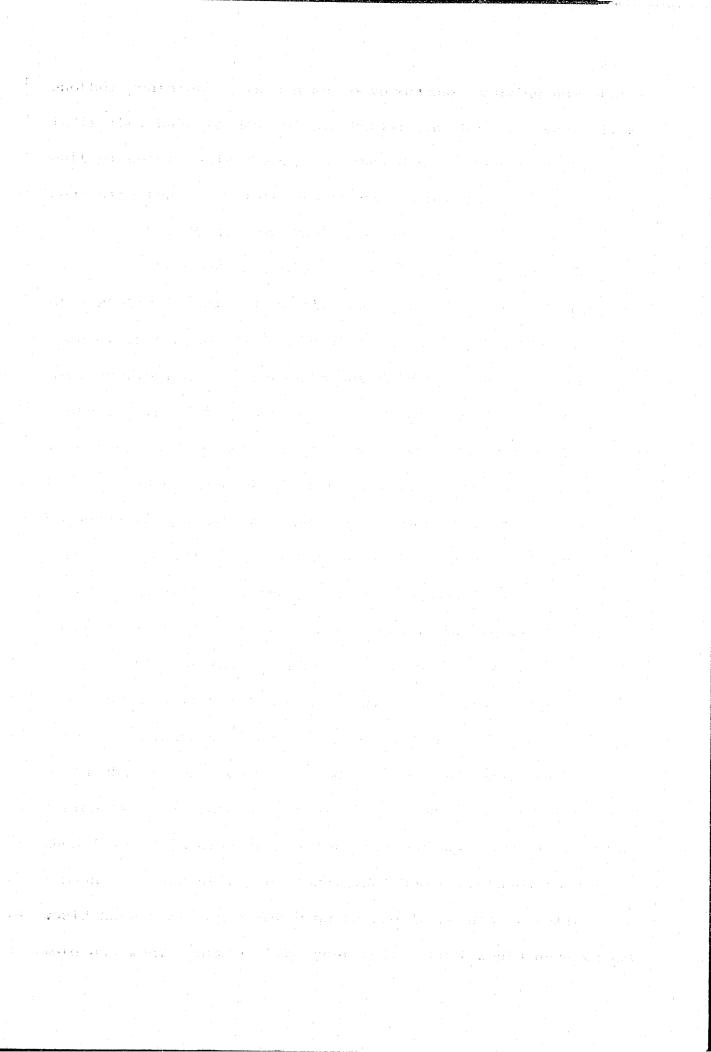
I in the recommendations and considered. One of the isons this was done was because the conference was only in duration. Conferees only had approximately 6 meeting time to develop these recommendations on these ious issues, and of that time, if you had a workshop 20 or 25 articulate, intelligent people who certainly thing to say about it, it was very, very difficult

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first of all where did the sample come from and the method of selection.

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3 It is not inconceivable to me that an ex-prisoner, given the discrimination in employment as related to prisoners 5 would find himself in a position that he would have to submit 6 to experimentation on the outside in order to get some money 7 in order to survive. Them doing that on the outside, though, 8 is totally different than them doing it in a coercive atmos-9 phere, because on the outside, clearly they have the choice not 10 to do it. They could go rob a bank to get some money. I mean, 11 there are other options there. But in the prison setting, you 12 know, to relieve the boredom, for instance, the choices are 13 limited, quite limited. In terms of making some money the 14 choices are guite limited within the prison setting.

15 But I think that in direct answer to your question, 16 I would need to know first of all the population that the sam-17 ple came from and the method of selection of those persons that 18 ended up in that research program.

19 MS. BROOKS: I would like to answer that a little bit, 20 too, and almost in the same tone, except that I was a volun-21 teer worker in Trenton State Prison for 6 months, and the only 22 people you ever find in the vicinity of a prison are people 23 who have something to do with it in some way or the other. I 24 spent 6 hours a week in that prison, in the best part of the § 25 prison environment. First of all, when people spend 5 or 10

1 years in prison life, there is nothing about those 5 or 10 2 years that make them comfortable in the outside world. So they 3 have created friends in prison. They tend to come back to prison. They tend to be affiliated with the prison cause. The 5 only people you find in a prison environment are former pri-6 soners, employees, and people who belong to volunteer groups and who usually belong to volunteer groups because they have had some relationship with the prison because they have had a relative, friend or something else happen, or are a community 10 participant.

11 So, in that arena that surrounds or that community 12 that surrounds most prison settings, you will not find former 13 ballet dancers. You will find people who have made some com-14 mitment to the prison. Many prisoners go back to prison be-15 cause there is no place for them after they get outside, and 16 of course there are people in prison who prefer it that way, 17 just as there are people in the Army who prefer it that way. 18 They prefer not to have to make decisions. You are probably 19 talking about a population who -- the prison statistics about 20 the number of people who have been there or in some other 21 institution a good 60 or 80 percent of their lives is pretty 22 high. There is something so debilitating about that experience 23 that life on the outside is sometimes not comfortable. So, 24 yes, you would get -- and all the other women and men I knew 25 who were volunteers in that prison were there for only one of three or four reasons. They had had a relative in prison and

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1	were sensitive to the conditions and therefore wanted to con-
2	tribute something; they were aching for a job or had a relative
3	or friend who worked in the prison and had been drawn in there
4	by that concern; or they were former prisoners. They make up
5	a large part of the voluntary force that works in prisons after
6	their time is served.
7	DR. COOKE: I don't know what Arnold's setting is
8	like. Is it a prison setting?
9	MR. JOINER: No, not at all.
10	DR. COOKE: No; that is why I think what you say
11	must be true about the prison setting, but this question was
12	directed at people who had nothing to do with
13	DR. RYAN: But Bob, he did do research in prisons
14	prior to that period of time.
15	DR. COOKE: He had done it.
16	DR. RYAN: So his contacts may very well have been
17	based on the kind of socialization that Ms. Brooks is talking
18	about.
19	DR. COOKE: But the setting was completely separate
20	from prisons
21	DR. RYAN: Yes, right.
22	DR. COOKE: and there were ads to college students.
23	as I understood, and a number of individuals other than just
24	prisoners.
25	DR. RYAN: Ms. Height, please.

15 1 MS. HEIGHT: There is one thing that I think hap-2 pened -- I happened to have been in Mr. Joiner's group, which 3 was an effective group, and in that group there was someone who had worked with the lawyers who dealt with the situation 4 5 in Attica, who was a woman legislator from the State of Louisiana who I thought was very helpful in pointing out the way in 6 which a person making decisions in a state legislative body is 7 8 constantly confronted with attempts to get legislation through She felt that this was almost like a learning ground for her. 9 10 There were others, a prisoner and so on. 11 One of the things that I think is somewhat mentioned 12 in the summary, and I find difficult for the Commission to deal with specifically but I think it represents sort of an 13 undertone that was all the way through. It was the recognition 14 15 that the disproportionate numbers of people from lower class, particularly non-white groups, were in the prison population, 16 and the real feeling that there is sort of a moral obligation 17 18 to recognize that the society that denies them opportunity also expects them to feel a feeling of responsibility to be of bene-19 fit to the society. This, along with the coercive climate, 20 was for me one of the most difficult things to translate into 21 specifics as to how you deal with it. I think it is part of 22 23 the reality that keeps escaping us if we simply take it in terms of -- if we do not recognize it. 24 25 It does raise some kinds of questions. For example,

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there was a real fear that often there are racial breakouts in research that may not be necessary, but that the racial 2 breakout continues to support the very climate that creates 3 the discrimination that brings people to prison in the first place. In other words, the prison, as it was perceived, was 5 almost a mirror of the society and its lack of opportunity, 6 and then those who are part of experiments help to condone the 7 bases of the original denials, and I think this was a theme 8 that kept running through. 9

I didn't look again at Dr. Cooke's paper, but I 10 think in there there was a statement of this, and I think this 11 is one thing that I would hope we would somehow take into 12 account as we are looking at the whole matter of prison re-13 search. I looked for it. I see certain sort of fleeting ref-14 erences to it, but I think it is hard to get that to come 15 through with exactly the force that the 2 days or 2-1/2 days 16 of intensive work brought it forth. 17

So that, it was not just the research, but the way 18 that the use of the research also furthers the elements of so-19 ciety -- there is a simple statement here somewhere that says, 20 "It is agreed that the issues of prisoners and race are merged." 21 Now, that was a kind of recurring theme, and if you look at è o 22 the racial distributions of the prison population, the racial 23 distribution of the officers in the correctional system and å 24 so on and so on, you see the basis for this. Bou 25

1 I think this is one thing I would hope we could have 2 very much in our minds so that -- in other words, as people 3 were saying, it is almost like saying that you have more Blacks 4 in prison and therefore more Blacks being in prison may make 5 the prison more attractive as a source for experimentation be-6 cause of the devaluation of this part of the population. 7 There are tremendous overtones through this report, and I would 8 hope that as we get the full report and the papers, that we 9 could read them, because I think therein lies a great deal of 10 feeling of almost distrust of whatever it is. 11 Also, when -- and I think this was mentioned at one of our earlier meetings -- when the conference was reported 12 13 through the media, the stress was on psychosurgery. In the meeting itself, it was predominantly about health delivery and 14 how the denial of some services -- if one is in prison and can 15 16 get those services, there again, it is the denial of something 17 that is given to prisoners that one did not get in the normal 18 course of life. I think this is kind of a recurring theme 19 that runs through this report. 20 DR. RYAN: Dr. Lebacqz.

DR. LEBACQZ: I think my question dovetails on Dr.
Height's concern. We have data sitting in front of us on this
table that indicates that actually in view of the proportion
of blacks and whites in prison, there is a disproportionate use
of white prisoners as research subjects, so that whereas the

population in a particular prison might be 56 percent black, only 30 percent of the research subjects in biomedical research will tend to be black. Now, with those kinds of statistics which have been thrown at us several times during the course of our studies, I have found myself wondering if -- well, 5 clearly that raises some questions about why there would be this disproportion in terms of involvement in biomedical re-8 search.

My question, however, is more specifically directed 9 to whether the minority conference, and particularly, perhaps, 10 your workshop, had more concern about behavioral research, 11 which would seem to me possibly not to break down this way. 12 I have no data before me that tells me what happens when people 13 do behavioral research or try out new behavior modification 14 techniques, or whatever, in prison, and I wonder if the con-15 ference was -- if there was a different feeling about the 16 rightness or wrongness, if you will, of behavioral over bio-17 medical research, specifically focused on the question of the 18 involvement of blacks as opposed to whites, or minority people 19 20 as opposed to whites.

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MR. JOINER: The workshop that I chaired did not get into a real sharp distinction between behavioral and biomedical experimentation. I think that most of the comments were pointed toward the behavioral experimentation because in 24 the particular group that I was working in that is where the 25

bulk of our experience had been, in the behavioral research. 2 The theme, though, running through was that whether it is з behavioral or biomedical, it ought to be halted or at least a moratorium placed on it. The only clear, distinctive thing that came out other than those two was the condemnation of psycho-6 surgery on prisoners. People were just asking for a total ban on any psychosurgery on any prisoner whatsoever. 8 I am not familiar with the statistics that you allude Q to. Again, I think it is important when you look at those 10 statistics to see where those statistics come from and the type 11 of research that is done on those persons that you are referr-12 ing to. Is it the safe kind of research or is that the more 13 dangerous kind of research? Are we talking about drugs that 14 have proven to be unharmful or the possibility of them being 15 unharmful to a large extent has already been deduced, therefore 16 there is a tendency toward bringing in white prisoners, or does 17 the more harmful type of research get done on minorities that 18 are in prison? I don't know. I just raise those questions in 19 terms of trying to put together the complete picture of the 20 origin of the figures that you stated. 21 I think with regard to the workshop, though, that 22 while we did not make a distinction between biomedical and 23 behavioral, that most of the comments were directed toward 24 the behavioral, but the theme dealt with both areas of research. a. 25 MS. BROOKS: I would like to address your statistics.

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I am sure they are right in the sense that if research in a prison environment are the goodies, then yes, there would only be 30 percent of the blacks involved in the goodies. Now, re-3 search as defined in this report talks about organized, com-4 mitted, contracted research. That is one set of statistics. 5 But even the drug manufacturers tell you they do all their 6 drugs, a great percentage of their drugs -- I am sorry -- on 7 the wider prison population. So that, if an aspirin company is 8 testing aspirins in the prison setting, and everybody that 9 comes up to the medical desk for an aspirin gets one of these 10 tested aspirins, then the prison research is being done on 11 whatever the racial composition of the prison is at the time, 12 as opposed to an organized research effort. 13

DR. RYAN: Excuse me. I don't think we ought to 14 play too loose with the data or what research is in prisons. 15 The Commission did make a site visit up there and did try to 16 make some determination as to why there was a racial imbalance, 17 and some Commission member may have a feeling about that, but 18 apparently there were different perceptions by the prisoners 19 themselves about whether or not they wanted to volunteer, as 20 21 well as -- yes?

DR. KING: A point of clarification. Do we have 22 statistics for any other prison with respect to participation 23 other than Southern Michigan prison? 24

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្លឹ 25 DR. GRAY: Yes. If I might, I was going to present

those statistics that were mentioned earlier a little bit later, 2 but just to clarify for the record, the statistics that were 3 being quoted are from the Southern Michigan State Prison at Jackson, that was visited. There is also a study with data 5 from four prisons which is going to be reported later today, 6 that has been done by the Survey Research Center. The statistics that we are quoting here are something completely inde-8 pendent of that study. We used the computer printouts that we 9 used to draw the sample to compile these statistics. 10 I can go through what we did later on, if we wish to 11 do that. 12 DR. KING: I just want to ask one question. Do we 13 have any nationwide statistics? Do we have comprehensive 14 figures with respect to prison populations and participation? 15 I think that there is a danger. My only point is that there is a danger in extrapolating too much from five prisons, and I am having trouble getting a discussion off on that basis unless

16 17 18 we have some other statistics.

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19 DR. RYAN: You are absolutely right. I think one of 20 the problems, of course, is that this is -- and I am going to 21 be misquoted again -- that this is almost a tempest in a tea-22 pot, because as I have told you, they stopped research in the 23 federal prisons and our statistics indicate that it is very 24 limited research going on in the United States in prisons, and 25 I think we ought to wait with respect to your question until we

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get the information from the four other prisons as well. Dr. Brady wanted to comment.

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3 DR. BRADY: I wanted to address the issue of therapeutic research, the distinction as we have discussed it here -5 in the past in the Commission, which I presume you are familiar 6 with, the distinction between therapeutic and non-therapeutic -7 research. There were some allusions to this in the minority conference proceedings. I am not sure that that issue was addressed directly, and I would like to get some feeling for 10 what the posture would be in that regard, that is, research which can be shown to be directly for the benefit of the inmates 12 involved in that research. I want to pursue that beyond the 13 biomedical, because I think it is even more relevant to the 14 behavioral research area, but what is the posture of --15 MR. JOINER: Well, to me, again, the lines are kind 16 of fuzzy. I don't see -- when a prisoner participates in any 17 type of research, for the most part, I am sure you see some 18

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19 DR. BRADY: Let me give you a clear line, so it 20 won't be fuzzy. At the Addiction Research Center in Kentucky, 21 we are talking about addicts who are prisoners and who have 22 direct investment in the research process to alleviate their 23 illness.

type of advantage in it.

MS. BROOKS: Are you speaking of the place in Lexing ton?

1 DR. BRADY: I am talking about the place in Lexing-2 ton. 3 MS. BROOKS: And you say that the prisoners would 4 directly benefit from the research. 5 DR. BRADY: Therapeutic research having to do with 6 addiction on the prisoners who are addicted. 7 MS. BROOKS: Is that the place where one of the 8 things that was developed was Methadone as a way of treating 9 heroin addiction? 10 DR. BRADY: No, it was not developed there, but it 11 was tested there. 12 MS. BROOKS: It was developed in Fidol (?) in New 13 York, for the most part. 14 MS. BROOKS: But it was tested out at Lexington as 15 one of the direct benefit researches. 16 MR. JOINER: Participants in the workshop that I was 17 in did not address that as sharply as you have defined it. It 18 was not addressed in that manner. There was the recognition 19 that there is possibly some research that is beneficial to the 20 inmates, such as the case as you have presented, and also re-21 search that is supposed to have some type of value for society 22 at large, but there was no hard breaking it down in terms of 23 "this is good and this is bad, and we will allow this and we 24 won't allow this, and we like this or we don't like that." We 25 talked about experimentation on prisoners, period. Again, like

I said before, we did not make any sharp distinctions at that 1 point between behavioral experimentation and biomedical experi-2 mentation in terms of sharpening the distinction, but there was 3 the recognition that there was some distinction. 4

Now, in the other workshop on prisons that had more -5 medically inclined persons in it, they got a little more into 6 that than our work. We had lay persons. We only had just a 7 bunch of lawyers and state legislators, prisoners, you know. 8 We didn't have the people with the M.D.s behind their name 9 who had all that medical terminology down pat and everything. 10 So we labored under that burden, for lack of a better term, to 11 come up with the --12

DR. BRADY: Do you think it is useful in your repre-13 sentations to consider that aspect of the problem? 14

MR. JOINER: Oh, yes, I think we need to look at that, 15 and I think that if we had another week or two that we could 16 sit down and really get in depth with this subject, that we 17 could really deal with that. 18

Just one other point I would like to make in regard 19 to these statistics, here. I was just looking over them real 20 fast, and I see where blacks represent 30 percent of the sub-21 jects, but I find that in terms of the housing units that these 22 subjects come from, roughly 53 percent come from the so-called 23 honor grade and trustee areas of prison, which mean the goody-24 good guys. The trustees are those persons that are super good 25

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1 to the extent that they watch the other prisoners, and the hondr 2 block are those dudes that are so good that they sit down in 3 the more comfortable spots in there, so it is just puzzling to 4 me why these people who have it so good, 53 percent of them, 5 would submit to all of this experimentation, when they would 6 have it better than, for instance, the ones in segregation, which was 5.2 percent of those persons as subjects, when the 8 segregation unit is usually the most dehumanizing stop in the 9 prison unit.

10 DR. BRADY: Them which has, gets. 11 MS. BROOKS: There was one comment in the other work-12 shop tapes with respect to your question, from a man who said 13 that a prisoner told him the last thing in the world I want to 14 do while I am in this prison is let them make me well, because 15 the minute I become well I am going to have to deal with being a well person and be tried for the crime I committed. 16 17 I would like to say that in the workshop on drugs as 18 it affects the community and minorities, there is an awful lot 19 to be said about one of the benefits of drug research, which 20 turned out to be Methadone. I think anybody from the minority 21 community or any other community who is exposed to the effects 22 and lives in the neighborhood of a Methadone program will tell 23 you that maybe Lexington, Kentucky should have never been, if 24 that is one of the benefits. 25

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DR. BRADY: They should not be held responsible for

Methadone. A lot of the work on Antagonis (?) is, however, being done at Lexington, Kentucky.

DR. RYAN: Dr. Stellar, please.

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DR. STELLAR: I realize the conference had a difference of opinion on this, but I am wondering whether our three colleagues here might give us their view of how they think of the possibility of overcoming some of the problems we have heard about through an accreditation system or a review board system.

MR. JOINER: If I may speak first on that, we dis-10 cussed that in our workshop, and the feeling was that any type 11 of evaluation process or review board created should include 12 prisoners. That in the past prisoners have not been in a posi-13 tion to make a determination of what is good and what is bad 14 for them, except like after the fact. There was a recommenda-15 tion that if such a body was created, that it include prisoners, 16 and in addition to that, that the composition of such a body 17 would also represent the cross-section of the population, so 18 that it would have more lay people on it that did not have a 19 vested interest in the research, possibly, that was going on. 20 One point that was strongly underlined was the participation of 21 prisoners, and I think one point someone made very strongly is 22 23 the distinction between a prisoner and an ex-prisoner, and pointed and pinned the prisoners' participation in that evalua-24 tion process and decision making body. 25

DR. RYAN: Our time is getting on, and I would like the commissioners to sort of sharpen their questions, and those who have not asked questions to raise their hands if they wish. Ms. Height, again.

5 MS. HEIGHT: I want to say to Dr. Brady's point that one of the points I think was mac. in this group very strongly 6 7 was that those who were prisoners should not be denied the 8 opportunity to participate in experimentation that might be 9 made available to other people. In other words, they have 10 their civil rights and they should not be denied the opportu-11 nity to determine whether they wish to participate. This was 12 some of the people who have been talking with the people who 13 were in the situation around Attica were very strong about this, 14 that you not be denied the opportunity to do something that if 15 you were not in prison you might be offered. 16 DR. RYAN: Dr. Seldin, please. 17 DR. SELDIN: Several meetings ago we were given a 18 rather dismal portrayal of some of the aspects of prison re-19 search as it has been conducted in the past, and I think every-20 body admits that this hasn't been one of the noblest features 21 of American activities. But I think it is often helpful to 22 look at prison research as if there were no prison research to 23 begin with. Let us assume for the moment that we were dealing 24 with a prison system without any prison research having been ž 25 there, and ask what might be done to, so to speak, make the life

of the prisoner a little more humane. Now, one would say that 2 the prisoner first of all, as Dorothy Height points out, has 3 certain rights, like anybody else. True, prison is a deprivation of rights, but nevertheless, a prisoner ought to have 5 certain rights, and one of the rights might be to participate in an experiment, without going into the details for the moment. Then there are prudential considerations, which are not neces-8 sarily evil. You point out the prisoner is very often bored, lacks a sense of purpose. It is not necessarily evil, although 10 it might be under certain circumstances, to give him opportu-11 nities to relieve his boredom. Then, of course, there is the 12 sense of participation in the mainstream of whatever society -13 offers on the outside that the prisoner, within certain limits, 14 may wish to participate in.

So that, one could, so to speak, in designing a system say what can we do for the prisoner to not deprive him further of his rights? What can we do for the prisoner along prudential grounds to make life a little less dehumanizing, and one of the things we might think of is certain work kinds of activities which might have rewards. Another thing we might think of is research projects.

Now, in the case of research, the real problem of
research is the question of free choice, the lack of coercion.
These values that I have mentioned might be counterbalanced by
the fact that there is a coercive overtone. The question I

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wish to put to you is this: Supposing one were to say, along 2 the lines also that Ms. Height mentioned, that one had an 3 accreditation model in which there were scrutinizing units. These scrutinizing units included, to be sure, prisoners, but 5 also people who are essentially hostile to the prison or to the prison system, let us say the NAACP to represent the black 6 7 group, or the American Civil Liberties Union, on the accreditation unit, to give it credibility so that the unit doesn't have 8 the appearance of a group of people who are essentially apolo-9 10 gists.

11 Under such circumstances one would gain confidence, I believe, that the kind of research going on in prison doesn't 12 represent the systematic exploitation, even though the surface 13 14 aspects may seem to say so. One would have confidence, for 15 example, that the American Civil Liberties Union -- and I am just pulling that out of the hat -- it doesn't have to be that 16 that these bodies would not allow themselves to be perverted 17 just for one prudential reason after another. Under such cir-18 cumstances, it seems to me that this might be argued, at any 19 20 rate, as a modest way to make life in prison a bit more humane. Certainly it would guarantee that the kinds of deprivation of 21 rights would not be going on just ipso facto because one says 22 23 in some general sense a prisoner is a prisoner. 24 MR. JOINER: Well, the workshop participants did not deal with that on point as you have described it. Speaking 25

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personally, however, I can think of a million ways that you could make the prison system humane and protective of the few 2 rights that prisoners have, rather than giving them the oppor-3 tunity of being a guinea pig. In short order, that is what 4 they become, guinea pigs. I think it would make more sense to -5 give a prisoner an adequate wage for the work that he does 6 while he is in prison. I think it makes more sense to allow 7 prisoners to have some association in terms of groups and or-8 ganizations in prison so that they can have some kind of con-9 trol over the limited life that they do have, that the kind of 10 living conditions be improved in the prisons. 11

But I would also say that in terms of research, es-12 pecially biomedical research, that if the pharmaceutical com-13 panies were so concerned about prisoners, that maybe what they 14 ought to do is go into the prisons, persuade the prison admin-15 istrators to turn them loose, and then hire each one of them 16 at \$15,000 or \$17,000 a year and give them a good job, some 17 security, some pension, some life insurance, access to a lawyer, 18 and all of those kind of things, and then let them do any kind 19 of experiments that they want to do. But they are outside the 20 prison system, they have got a job, they have some choice, they 21 can accumulate some meaningful income, they can really take care 22 of their family, and the pharmaceutical company is making an 23 investment in those persons that they can now say have willingly 24 decided they want to be guinea pigs for the newest drug that is ĝ

1 coming out on the scene. I have not seen at any point where 2 the pharmaceutical company has made any meaningful investment 3 in the bodies and personalities of those persons that become 4 guinea pigs. After they get out of prison, they can't get a 5 job at one of these companies. Do they have any priorities on 6 getting jobs after that?

7 I am saying that it seems to me that is one of the 8 kinds of commitments that the pharmaceutical companies could 9 make, that the other kinds of testing units, the psychologists 10 and psychiatrists who run in there and probe through their 11 minds, can make to these fellows, that they are going to give 12 them some meaningful jobs when they get out, something that can 13 help them return to society. I don't think that the option of 14 being in the honor grade or in the segregation or being shot 15 up with some malaria germs is an alternative. It has nothing to 16 do with freedom of choice or rights or anything else. 17 DR. RYAN: Any other Commission comments? Bradford 18 Gray wants to say something.

DR. GRAY: I just wanted to ask a question. We have heard a number of individuals and groups who have spoken against prison research on the basis that it is a coercive atmosphere and people have limited choices, and arguments of that sort. The question that I have, that we haven't asked any other people who have spoken in this vein but I think it is a reasonable question to ask, is to what extent should this Commission in its

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deliberations on this question consider the expressed views of 2 prisoners who have participated in research, about whether 3 research in prison should be done? That is, if prisoners who have participated in research -- and we are going to have some 4 5 data on this later -- I don't want to trap you -- overall have spoken well of it in the prisons that have been studied, if they 6 7 speak in favor of it and say they would like to see it contin-8 ued, to what extent should that view be considered by this 9 Commission? That is the guestion I have.

MR. BROWN: I think that view has legitimacy; but 10 remember, now, these people that you have asked in the prisons 11 are still there, and those that you ask in terms of the ex-offend 12 have a different opinion. So I think you really have got to 13 give it some thorough deliberation. I don't think you can make 14 a blanket statement about that. I think that has to be probed. 15 I would like to draw your attention to the preamble 16 on Workshop 7, and to read that preamble carefully in terms of 17 how the prison itself is viewed before you even think about the 18 kind of experimentation that goes on there. 19

20 MS. BROOKS: If it would be quicker for me to read 21 it, since I have it right here, I would be glad to read it. 22 DR. RYAN: We have it. Dr. Louisell?

DR. LOUISELL: I asked about when the moratorium would begin under your plan, but I think I neglected to ask how long you contemplate it would be necessary for the moratorium to last before an adequate determination of the relevant things could be made.

2 MR. JOINER: The recommendation was that there be a 3 moratorium. We did not attempt to work out the details of that. 4 I think that the duration of such a moratorium would be based 5 on the ability of a group to make the kind of determinations necessary to make a determination of whether it ought to continue or not continue. I don't think that by saying 2 years you could -- you know, just like this Commission has 2 years, 8 for instance, to operate, which puts certain kinds of constraints on you in terms of really exploring the issue that 10 has been set before you. The ideal is not to give any kind of 11 12 constraints on it, but to say that this needs to be done. 13 DR. LOUISELL: It would have to be indefinite, depending on developments? The period of the moratorium. 14 15 MR. JOINER: Well, the term "indefinite" seemingly 16 implies forever and ever. I would like to change that term to 17 one meaning that it is at the discretion of that body that is 18 making that determination; not necessarily indefinite. 19 MS. BROOKS: I would like to, in response to your 20 question, suggest that if you are not able to read anything else 21 in the report, the preambles to the workshop recommendations 22 will give you something, take some of the paleness out of our 23 attempt to commit this to writing. My impression from listen-24 ing to the tapes of this conference and my impression from reading all the material is that no one at that conference had 25

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any illusions or delusions about the effectiveness, necessarily,
of their effort or that they were qualified to judge under the
circumstances some very important issues.

When you ask how long were people suggesting the 4 moratorium should be, well, maybe -- how long should it be be-5 fore we are all free? I mean, that is one of those rhetorical 6 questions that says that no one could answer that without de-7 termining something. If an experiment that has been conducted 8 has some 5-year effects, as we know some medical practices do, 9 maybe that is the extent of the moratorium on that particular 10 biomedical experiment. If the taking of certain pills, say, 11 for instance, in women's prisons, the effects of which will not 12 be seen for 10 years, maybe that is the period it should be. 13 But that is the kind of question that I don't think anyone 14 could attempt to answer. 15

One of the important things about the preambles in 16 the workshop recommendations is they will answer a lot of your 17 questions about the actual recommendations. The preambles set 18 the environment and the feeling of the group, usually, about 19 how they felt about everything they said after that. This 20 preamble says that very clearly some of us think that prisons 21 have to be abolished, that we shouldn't even be talking about 22 research in prisons, that we should be talking about the abol-23 ishment of prison, and then go from there. 24

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But we recognize that that is not reasonable, so

1 therefore we are talking about this, and each preamble or policy 2 statement will tell you where people's heads were when the recommendations came in. 3 DR. RYAN: I think I will call on Dr. Jonsen. We 4 are going to have to terminate this discussion now. Al, please. 5 DR. JONSEN: In recognizing that the recommendations 6 7 range from a total abolition of experimentation to the recommendation of a moratorium, we are faced with a certain perplex+ 8 ity. People who say to abolish it totally, I assume would do Q so on the basis of some principle; they see it as impossible 10 because of lack of informed consent or coercion, they see it 11 as a way in which the majority society utilizes or uses the 12 minority and subjected population, and they come up with the 13 14 conclusion that it is bad thing, stop it. But anyone who recommends a moratorium is simply asking for a delay, and therefore 15 is apparently not clear that it is all bad. They must see some 16 positive features. Now, the minority report as we have it does 17 not indicate what positive features those who only recommended 18 a delay might have seen. Does the transcript indicate what 19 positive features might have been thought of? There were 20 some people who said it is not all bad, stop it. Why was 21 22 that?

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MS. BROOKS: Because 200 people met for 6 hours and attempted to deal with some vital issues, and the transcripts were they transcribed would probably reflect the same sort of inability initially in such a short time to gather some firm

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feelings. These people did not have the support of a staff of people to provide research the minute they asked for it. We were not able, under this contract and under the conditions, to be able to say here are the prison statistics on that. We 5 didn't have those kind of resources.

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6 DR. JONSEN: Would you say, then, that the reason 7 why some people said a moratorium was merely that they didn't 8 know enough about it or that some people recommended a mora-9 torium because they said; wait a minute, we think that a con-10 sideration like giving the prisoners a chance to do something 11 interesting to relieve boredom is sufficient enough for us to 12 say maybe there is a reason why research ought to be continued 13 under proper controls? In other words, I need some kind of a 14 determination that tells me moratorium means we just don't know 15 enough or that moratorium means there is something good about 16 it and let us see if it can be continued under certain circum-17 stances.

18 MR. JOINER: Again, I speak from the workshop that 19 I chaired and based on conversations that I had at the confer-20 ence with other people, and the feeling was that if you call 21 for a complete ban of all experimentation on prisoners, as 22 laudable as that was, that the power interests in this country, 23 the money interests in this country, would not allow that to 24 come about. I mean, and then with the realization that that à 25 goal was not one that would be achieved in the very near future, then the next option became a moratorium so that

concerned people and people who have the kind of task that you . 1 2 have before you could sit down and do some in-depth kind of study to see if this long-range goal that we project ought to, 3 in fact, become the policy that this country adopts as relates 4 to experimentation on prisoners, or if there was, in fact, some 5 redeeming social value in being a guinea pig. 6 7 That body had do do that, but it was not out of con-8 cern for the most part that they can make some money and they can do this and they can do that and therefore we ought to 9 study this some more, or we don't have all of the facts, be-10 cause most of the people really thought that from the moral 11 point of view that they were in essence serving as a kind of a 12 protector or protectors of the Black community, some of whom 13 would end up in a prison at some point, and maybe even some of 14 those people that were in attendance at that meeting would 15 end up in prison at some point, and from that moral perspective 16 and from the view that we were asked to sort of form a protective 17 kind of policy, that we would not want our people subjected to 18 19 those types of dehumanizing experimentation. 20 DR. JONSEN: You make a point that differs from either of the two that I made. That is, the decision was largely a 21 22 practical one relative to the politics of the situation and 23 realities of the politics.

24 MS. BROOKS: I would like to refer you to something â 25 that is in the report which is a letter sent to us by the

Deputy Commissioner of Prisons from the State of New York, Louis Douglas, as it reflects his participation in the confer-3 ence and his feeling about it. He is Deputy Commissioner and knows that he doesn't know enough to make a firm recommendation 5 in this area and suggests that that was only scratching the 6 surface.

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7 DR. RYAN: Ms. Height? Positively the last word. 8 MS. HEIGHT: I think if you look at the kinds of 9 items that Workshop 7 suggested needed to examine, you get a 10 little bit of a sense what people were saying. They said, we 11 don't know that much about it, what is the purpose, why is 12 there this research, and all this. There is a kind of sense 13 that there is a veiled something going on that is affecting a 14 lot of people, and that very little is actually know about it, 15 and that there is very little disclosure of what it is all 16 ! about. If you look at the kinds of things, they seem like sim-17 ple items, but they really are those same elements with which 18 we are concerned, and those are the elements that came up again 19 and again. People said we need to know why is this, what is 20 it, how do they determine who will be selected, and what is 21 the role of professional groups, what is the role that legis-22 latures play. So you have got political and social and economic 23 as well as some of these other factors that deal with research 24 itself coming into the picture.

DR. RYAN: Thank you all very much. We have other

speakers this morning. You are welcome to stay with us. 2 The next speaker is Dr. Leonard Glanz from BU. There is a report under Tab 15 entitled "Legal Status of Informed Consent in Human Experimentation; Prisoners." It is a large document which I believe was distributed to the Commission ó members prior to this meeting, so that some of the Commission 7 members may have had an opportunity to read it. Perhaps you 8 would like to give us a synopsis or a short summary and then 9 throw it open for questions.

10 DR. GLANZ: I just want to say this is the biggest 11 table I have ever seen in my life, really quite incredible. 12 I am glad that Mr. Joiner made a distinction between the policy 13 considerations and ethical and moral considerations, and the 14 legal considerations concerning informed consent, because we 15 really didn't examine the policy considerations or the moral 16 considerations. At least some argue that since we are all law-17 yers at the Center that we can't debate moral questions with 18 any authority, but we tried to approach the issues strictly 19 from the point of view of could a prisoner give his informed 20 consent if it was decided on the basis of policy that experi-21 mentation should be done, should be done in prisons. 22 We went about this a couple of ways. One thing we 23 tried to look at is some of the work that has been done on 24 prisoner motivations to participate in experimentation, and ີ້ສີ 25 some of that is okay and some of that isn't so good. But

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generally, the things that have been discussed earlier today 2 concerning motivation come through over and over again. That is, money plays a part; and there is some discussion of altruism, prisoners wanting to help society or repay their debt in 5 some way; the prisoner experiences some monotonous and this is 6 a way for them to have some excitement placed in their life, and so forth.

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8 The trouble with studies on motivation is that they 9 talk a lot about what motivates all of us to do just about any-10 thing that we do. The reason why people work for a living is 11 money, for example. It is very hard to draw the distinction 12 between motivation and coercion or duress, or undue influence. 13 We did try to do that. Before I go on, I just want to say that 14 Lazanya (?) did a study on volunteers who were not prisoners 15 to see why they participated, and he found that a high rate of 16 free living subjects displayed certain serious mental illnesses 17 and he didn't know how free they really were to give their in-18 formed consent, as a result of that.

19 But the problem of motivation, I think, does blend 20 in to the problem of coercion. We see whether or not the pri-21 soner is motivated by undue influences or he is motivated by 22 fear or threats that his situation at the prison will be worse 23 or not get any better as a result of his not participating in 24 experimentation.

When we look at coercion, we see if the situation is threatening or threats are made. I think one has to look at

1 prison environment itself. I don't think that it is the ex-2 periment itself that is coercive but the environment that the 3 prisoner comes from that might make his participation the re-4 sult of coercion. I think you have to look at such things as 5 is the prison overcrowded and unhealthy, or just generally 6 dangerous. Is the food inadequate, by that meaningthat it is 7 not adequate enough for them to have a proper diet, a nutri-8 tional diet. Is the prisoner able to maintain minimal standards 9 of personal hygiene with the resources that are given him in 10 the prison? We look at that type of thing. 11 If the answer to that is no, but that these amenities 12 are available to him as a result of his participation in re-13 search, then I think that the argument that coercion exists is 14 strong or that duress is liable to exist is strong. It would 15 be similar to saying that unless you participate in the experiment, we will force you to live in subhuman conditions. I 16 17 think that if it is put that way, that we can see the coercive 18 element involved.

19 I think that this points out the necessity for accreditation, which was just mentioned shortly. The first 20 21 draft of the federal regulations on experimentation on prisoners 22 talked about accreditation. The second draft revoked it. They said that there was some problem, stating that this would con-23 stitute interference with autonomous state institutions by the 24 Federal Government. I don't really buy that. I think that the 25

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regulations which exist still interfere with those autonomous 2 institutions to a certain extent. They say that they are not 3 free to do to prisoners or with prisoners what they would like 4 to in terms of experimentation.

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5 But I think it is very important to go in and make 6 sure that the prison atmosphere itself is not so poor that a 7 prisoner is actually forced to participate in the research, to 8 be forced to move to the cleaner, healthier, more livable area 9 where the experimentation is conducted. I think that accredi-10 tation is a very important part of the safeguards that need to 11 be instituted if one were to allow prison research. I think it 12 is important to make sure that the informed consent is given 13 voluntarily and freely.

14 The issue of payment, I think, is a similar one, 15 the issue of financial reward, and again, financial reward mo-16 tivates a lot of people to do a lot of things. Evel Kneival 17 probably wouldn't jump the Snake Canyon for free. Also, I think 18 one has to look at why the money is required, why the money is 19 needed. Again, I cite a case that hasn't been tried yet deal-20 ing with a house of corrections, a case brought by the ACLU, 21 in which money had to be obtained in order to purchase food to 22 supplement the prisoner's diet. The food could be obtained in 23 the commissary, and but for obtaining that food, the diet would 24 be inadequate. It would be a non-nutritional type of diet.

They also point out in that case that really the only

way to obtain enough money to supplement that diet and to get the things that are needed to maintain personal hygiene and 2 health is to participate in experiments. I think as a result 3 of that, that type of offer of money would be coercive. I 4 think that if the only way the prisoner could receive funds is 5 to participate in experimentation and he must receive those funds in order to maintain his own health, for example, then he 8 really has no choice but to participate, and that is what was 9 being argued in that case. Again, it hasn't gone to trial so we don't know what the judge said, but we can use that as an 10 11 example.

This doesn't mean that the money is always a coercive 12 force, even though it might be nice to have. I think we could 13 14 ask is the money truly given as a reward instead of given as something that the prisoner must obtain. This comes into the 15 accreditation aspect, also. I think one would have to deter-16 mine whether or not there are other jobs in the prison, whether 17 or not those jobs paid a rate of remuneration similar to the 18 19 participation in experimentation. In effect we are saying that the prisoner has an alternative, and if the prisoner does have an alternative I don't think that payment per se constitutes 21 duress or coercion. 22

23 Now, on the behavior modification side of the problem, there are strange problems and difficult problems. one can 24 25 look at the entire prison situation as being a behavior modification experiment. We don't know today whether or not prisons

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work, that is, do they reduce crime, do they deter crime, but certainly their purpose is to modify behavior of the people that we put in them. The other problem is trying to decide whether it is the experimental nature of behavior modification programs that have been discussed and we will be discussing that offends us.

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7 We could raise the hypothetical that if the prisoner 8 does something which is not liked by the prison authorities, 9 gets into a fight, and is placed in solitary confinement, what 10 safeguards are needed, and would those safeguards change if we 11 had a social scientist there and we say when a prisoner gets 12 into a fight and he is put into solitary confinement, we want 13 to see, we want to measure, we want to test it to see if his 14 attitudes change or if his actions change, and does that then 15 become experimental?

16 I think when you look at the behavior modification 17 cases, like Mackey v. Procunier and Knecht v. Gillman the 18 cases which use Anectine, the drug that stops breathing, the 19 cases that use Apomorphine, that causes long periods of vomit-20 ing for aversive therapy, I think what one finds is that the 21 courts aren't really emphasizing the experimental nature of what 22 is being done. I think they emphasize the fact that they are 23 outraged by what is being done. The court says that we all 24 know that vomiting for an hour in front of other people is a 25 dehumanizing and painful experience, and therefore we are going

1 to protect the prisoner against that sort of thing. They don't 2 really emphasize the experimental nature of it, but those cases 3 do. They are important cases for us because they do state 4 that the prisoner can consent to that kind of experimentation. 5 They do not say that the prisoner is not capable of giving his consent, and indeed they say that although this may be cruel 6 7 and unusual treatment or punishment when a prisoner doesn't 8 consent, if he does that it no longer is such cruel and unusual 9 treatment.

Therefore, we at least have a couple of courts saying that prisoners can consent to this type of treatment. They don't really get into the experimental nature of it very much, but they say before we do these things to a human being we are going to make sure that we have his consent, that we don't want it being done involuntarily.

10 Clonce v. Richardson (?), which is another behavior modification case, deals with the Start program, in which they 17 18 didn't use physically invasive procedures, but I am sure you are all familiar with it by now, that they set up different 19 20 status levels, and as you progress through status levels you 21 have more and more privileges. At the lower status levels your 22 reading was restricted, your freedom to move was restricted, 23 more than at the higher status levels. 24 There the court didn't discuss the question of whether or not the prisoner had to consent. Indeed, it said that 25 that issue was mooted by the fact that the program was no

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longer in action when they heard the case, so they wouldn't 2 discuss it at all. But what they did say is that there are 3 certain due process requirements that there had to be before 4 the prisoner could be transferred into a condition that was -5 less favorable than the one he was in already. Again, the 6 experimental nature of it isn't what seemed to bother the court. 7 It is the fact that the prisoner was being transferred to a 8 less favorable situation than he was in before, and there is 9 at least one other case that discusses the fact that before one 10 can discipline prisoners and take away some of their privil-11 eges, that he should have certain due process protection.

12 On the other extreme -- and I am not sure this is a behavior modification case. It deals with psychosurgery. Some 13 14 people allege that that is not really behavior modification. 15 But say that it is an extreme form of behavior modification. We only have the Kamowitz case, we really don't have cases 16 17 dealing with prisoners. In our Center's report on mental pa-18 tients, we will discuss this in greater detail. But in Kamo-19 witz we are dealing with a mental patient who was institutionalized for 17 years. What the court found there is that that 21 prisoner, because of the nature of the institutionalization, 22 could not give his informed consent, which goes right to the 23 question that we are dealing with. The court says that all the aspects of the prisoner's life are decided for him, he has lost ŝ 25 his ability to make decisions, that institutionalization strips you of your freedom to act, and therefore he can't give his

consent to this experimental procedure, this irreversible ex-2 perimental procedure, I should say. 3 The court did something which is somewhat irrational, I think, anyway, and that is they said that if the procedure 5 were no longer experimental, that is, if we knew that it changed a person's behavior or if we knew it flattened emotions or if 6 7 we knew whatever it was that we are supposed to know about it, 8 so therefore it wasn't experimental, then the fact that the 9 person was confined for 17 years becomes irrelevant, that he 10 could consent to it. It is as if institutionalization no longer 11 counts because it is not experimental. This goes to the point 12 that I was making before, and that is I am not sure that in the 13 behavior modification area it is the experimental nature of the 14 problem that counts, but what is it that we are doing to these 15 people.

16 I think part of that is a result of a question that 17 was asked from this side of the table before, about behavior 18 modification, and that is I think that behavior modification 19 is probably seen as therapeutic experimentation. That is that 20 the prisoner, in theory, will benefit from it. He will no 21 longer be violent, so he won't go to prison later on. He will 22 no longer be a pedophile. That if these things work, the 23 prisoner will be better off. I think therefore the courts are 24 less concerned with the experimental nature of it because there 25 are some therapeutic aspects to it.

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2 sent as long as there are certain sareguards, and just to name 2 we: 3 a few, I think that accreditation is an important one to make 3 111 4 sure that the particular prison environment is not inherently 4 5 coercive. If you look at the Army regulations, interestingly 5 is 6 enough, before they allow any experimentation at their facili- 5 is 7 ty they do require a site visit by a medical officer and by a 5 so 8 legal officer. It is not clear what they look for and what 7 bea 9 br. RYAN: I wonder if we could break in now and let 9 we 10 DR. RYAN: I wonder if we could break in now and let 9 we 11 the commissioners ask you questions. 10 wit 12 DR. GLANZ: Sure. 11 12 vic 13 DR. COOKE: I would like to ask you I have com- 13 unw 14 DR. COOKE: I would like to ask you I have com- 14 the 15 ments on three issues. How would you first, a little pre- 15 that 16 amble. In general, goo		40			
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indeed the greatest free choice of all the people there and were choosing to participate. That is one item that I would like you to comment on.

The second, in regard to behavioral modification, is is the outrage about the use of behavioral modification and so forth in part, at least, or a significant part at least, because the data substantiating its benefits is relatively worthless, and if so I would like to ask the question how do we get the data to show that it is worthless or not worthless without the conduct of research?

The third is an even worse Catch-22. We have individuals who are institutionalized because, let us say, of their unwillingness to choose treatment that might take them out of the institution, electroshock therapy, for example, and yet that patient as he remains longer and longer in the institution, according to your presentation, loses his ability to make choice and therefore can never accept therapy. Now, how do we handle those kinds of situations? Would you comment, please? DR. GLANZ: I guess you call that a Catch-66, three

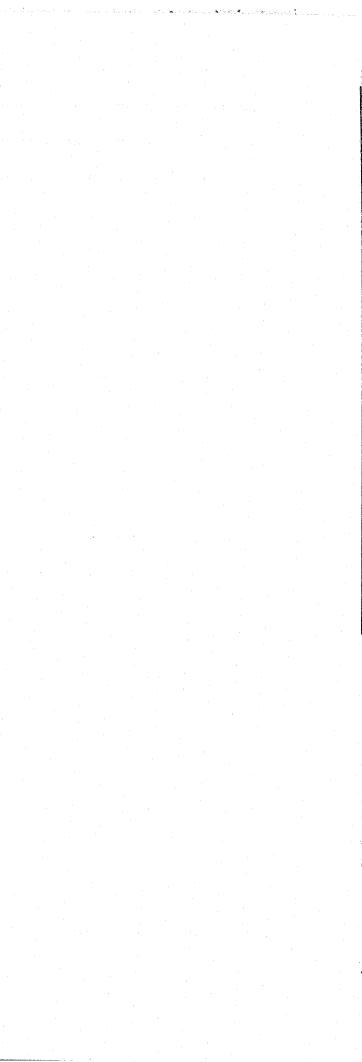
DR. GLANZ: I guess you questions.

DR. COOKE: In terms of those who participated in Jackson, I have no idea. I mean, I think you would have to talk to them and you would have to talk to non-participants and see why they participated. I am not necessarily saying, again, not talking on policy issues, not trying to give you new data,

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DR. GLANZ: To which point?

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DR. COOKE: To the point of having something accepted and customary and so forth. That is the problem we are struggling with. If we couldn't do anything to anyone until we have some information as to whether it is --

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6 DR. GLANZ: Well, I think there are a couple of ways 7 out. There are a couple of ways out for me, anyway. One is 8 to say that the Kamowitz court may not reflect the attitude of 9 all courts, that there concept of institutionalization as a broad concept may not be very good. One, I think, can examine 10 11 a person on a case-by-case basis and ask has he -- whatever 12 way this is done by behavioral scientists -- has this person been stripped of his ability to give his consent because of the 13 impact of the institutionalization on him. In that case you 14 15 are probably dealing with an incompetent person and then you get into the problems of guardians and all that, which I cer-16 17 tainly don't want to talk about right now.

18 But I think that is the result of saying -- the 19 problem of institutionalization -- is that if it does exist 20 for a particular person, then we have to ask can someone else 21 consent, not that that by definition means that it can't be 22 done. But while we are doing research, if you ask how do we 23 find out if these things work, if the only problem were one of 24 institutionalization, then I think at least initially you do 25 it on people who haven't been institutionalized for 17 years.

You do it on the person soon after the institutionalization, if you decide he is an appropriate candidate for that sort of research.

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DR. RYAN: I would like to break for coffee in a few minutes, and I want to call on Pat King first, and then I am keeping all your names down and we will resume the questioning afterwards. I think it is going to go on for a little while. Ms. King, please.

9 DR. KING: If I am permitted a preamble, I wanted to say, following Bob Cooke, that I think the issue of who volun-10 11 teers and why they volunteer -- I agree with the speaker -- is 12 extraordinarily complex, not to mention, in certain environ-13 ments, that to be able to participate -- something we have not 14 discussed -- in a research protocol or experiment may indeed be regarded as a privilege in an institution that has few pri-15 vileges. So, that only makes the motivation, I think, more 16 17 complex.

18 I have two questions. One, you propose some system of accreditation. My question is have you given any thought to 19 20 or have you done any study of how one effectively enforces an 21 accreditation system? I think -- let me explain why I ask 22 that. In principle I have no difficulty with what you propose 23 about dealing with certain -- trying to modify an environment. 24 In practice, my own experience with accreditation systems on 25 institutions that are nowhere near as closed as a prison is

that they tend to be ineffective , they tend to set minimum 1 2 standards, and that even the minimum standards are subject to interpretation because we can only go so far in articulating 3 certain types of minimum standards, those that we cannot quan-4 5 tify, for example, which can be extremely difficult to articulate. 6

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My second question is, in the court opinions that you 7 cite, excluding Kaimowitz that deal with behavioral modifica-8 9 tion, behavioral therapy, et cetera, you mentioned that the courts did not appear to be concerned with the experimental 10 nature of what was done, but merely what was done. I would 11 like to ask if there is anything in those court opinions that 12 indicate, however, that the judges may be concerned about the 13 beneficial aspects of it, which is a different question than 14 the question of experimentation. 15

DR. GLANZ: I think with accreditation, if we can 16 talk of the question of standards, to begin with, what we should 17 look for, what should the rates ofpay be, what should the qual-18 ity of food be, do we have dieticians determine what the 19 caloric intake should be, the protein intake and that sort of 20 thing, getting around that I think that in terms of enforcing 21 it, that prisons are in a way in a better situation to enforce 22 it than hospitals or nursing homes or things like that, because 23 you have a built in group of reporters, and that is the pri-24 soners themselves. I think that the purpose of accreditation 25

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would be to assure that the standards within the prison are 2 relatively high, that they did meet certain standards which 3 would make the life of the prisoners better, and that if they did not you would say that the experimentation could not go on. 4 5 I think that certainly on an accreditation committee you would 6 want prisoners in that institution. I think there is no question about that. But I also think that you would want to no-8 tify prisoners of what the standards are and that when they see the standards falling below a certain level, which would 10 affect them directly, that they are to report it. 11 DR. KING: Can I ask for a point of clarification, 12 since he has clarified my question? That is, then what you 13 are proposing means that if this Commission were to go the 14 accreditation model route, assuming we could come up with 15 standards, that we would have to, in order to assure some ability to monitor that or enforce that, at the same time as 16 17 a part of the standards or as a part of a separate system, 18 insure a mechanism or attempt to impose a mechanism for internal 19 decision making or participation among prisoners themselves. 20 Now, I am not trying to specify any form. I am not going to 21 get into prison unions and prison committees and all that sort 22 of stuff. I am just asking -- you are saying that we have to 23 go further than dealing with just the research aspects of it 24 and will have to also insure some type of effective internal å 25 reporting back in order to make an accreditation system work.

	1	DR. GLANZ: Oh, I absolutely think that is the case,	
	2	because as I tried to stress earlier, I think that the coercive	
	- 3	factors that exist in prisons are the prisons. It is the pri-	2
	4	son itself, not just the experiments that go on in prison, but	3
	5	it is the prison that produces the coercion. There are other	4
	6	ways to do it, such as you can have an accreditation committee	5
	7	make spot checks of prisons, unannounced spot checks, to see	6
	8	what was going on. In a way, that could be easier also than	7
	9	the type of accreditation that has gone on, say, for payment	8
	10	for Medicare programs, accreditation of nursing homes and hos-	9
	11	pitals. I would imagine there would be many fewer prisons	10
	12	that apply for accreditation for this. One reason is the money	11
	13	to bring them up to standard, and once they were up to standard	12
	14	it would cost them a lot more money to maintain those standards	13
	15	and I think that would reduce the number of prisons that had	14
	16	experimentation going on. Therefore, I don't think it would be	15
	17	as difficult to have accreditation committees make suprise spot	16
	18	checks as it is for other accreditations.	17
			18
	19	DR. RYAN: Joe Brady, one brief comment.	19
	20	DR. KING: He didn't answer my second question.	20
4	21	DR. GLANZ: Oh, the beneficial aspects. No, it	ן 2
Compa	22	doesn't, when I think about it, no. The court said that the	¹⁰⁰ 22
Керогіпд	23	prisoner can consent to it and that is it. If you explain what	22 23 23 24 24 25
ers	24	you do know about it to the prisoner and you explain that he	troday 24
BOW	25	can withdraw from it at any time, then he can consent to it.	mog 25

DR. RYAN: Joe Brady wanted to make a quick comment. DR. BRADY: I just wanted to comment on Dr. Cooke's earlier "When did you stop beating your mother?" question, the point that the data shows that behavior modification is worthless as the reason for banning it from the prisons. Quite the opposite. The data does not show that it is worthless, and the major basis of concern in my experience is that it works. DR. COOKE: The data were worthless, I said, not the behavior modification. DR. BRADY: You said the data shows it is worthless. DR. COOKE: Oh, I meant to say that the data itself is worthless. DR. BRADY: You stand corrected. DR. RYAN: We will reconvene in 15 minutes, please, and continue with the questioning. (Brief recess.) DR. RYAN: I wonder if we couldn't please resume our discussion with Dr. Glanz, and I would like to call on Dr. Jonsen, please. Al, did you have a question? DR. JONSEN: Yes. Mr. Glanz, two questions. First, you mentioned the Jessup House of Corrections case. Could you expand a bit on that? Are there other issues in that case than the one which you mentioned, namely the coercive aspects of the money paid where so few items are provided by the pri-

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son?

1 DR. GLANZ: There are a lot of constitutional argu-2 ments that are made. It is hard to say really how forcefully 3 they were made and how forcefully they will be accepted, but 4 basically I think the case in a lot of ways was brought because 5 of the poor prison conditions, period. There were some other 6 problems concerning other prisoners getting infected, and if 7 someone went to the infectious diseases area and came back, it might be that other prisoners who weren't participating in the 8 9 experiment itself might be subject to certain risks which they hadn't consented to. 10 11 There were problems that prisoners wouldn't be paid the full allotment of money if they withdrew from the study, 12 13 and so it was alleged that people were sick and weren't reporting themselves to be sick and therefore weren't getting adequate 14 care. There were a couple of other issues, but I thought it 15 particularly well illustrated the problems of the duress and 16 17 coercion. 18 DR. JONSEN: You selected that one because it was illustrative. 19 20 DR. GLANZ: Right. 21 DR. RYAN: Dr. Lowe has a technical question. DR. LOWE: You are talking about the pleadings, 22 Company right? 23 DR. GLANZ: Yes. 24 d al 25 DR. LOWE: The case has not gone before the court.

1 DR. JONSEN: Yes, I understand that. 2 DR. LOWE: I wanted to be sure that was clear. 3 DR. GLANZ: That is why I say in the paper that if 4 these are found to be true, if this is indeed the case, then 5 we can say that --6 DR. JONSEN: I understand. Secondly, with regard 7 to Kaimowitz I have been told that one generalizes from cases 8 at one's peril and at the peril of the logic, and I assume that one ought to read Kaimowitz relative to the situation of John 10 Doe and not necessarily to any other situation or to any other person, and that the 17 years is an important feature there. 12 One ought not to say that prisons or institutionalization is 13 inherently coercive as a conclusion from that case, but merely 14 that Mr. Doe, given his situation, his state of mind and his 15 experience over 17 years, was not judged capable of making a decision. This might appear to you a very bizarre interpreta-17 tion of the court, but I have been puzzled by the court's pe-18 culiar distinction between experimentation and non-experimental, 19 and it seems to me that perhaps one way of reading that is to 20 say that John Doe ought not to be put in a situation where he 21 is confronted with possibles and probables. That having been 22 for so many years in a situation where everything was yes and 23 no, it was judged that he ought not to be put in a situation 24 where he would have to make judgments about risks, and that a 25 that might not be the case if someone could come to him and say

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1 this procedure will in fact help you. That his consent there 2 would not be compromised by the variety of possibilities that 3 would be presented when an experimental situation were proposed 4 to him. Does that kind of a distinction make any sense to you?

5 DR. GLANZ: In a way the court alludes to that sort 6 of thing when it says that he had been in prison for 17 years 7 and that if he wanted to get out, something had to change, and 8 this might help him to change, that it was presented to him in 9 such a way that it would appear to be beneficial and that 10 therefore he might be able to be released after he had psycho-11 surgical procedure. I think if that is what you are saying, that he wasn't really presented with choices because he couldn't 12 13 make choices, that it was presented to him by saying that this will help you -- is that the point that -- ? 14

15 DR. JONSEN: No. I am really suggesting that the court judged that this man was not capable of balancing a com-16 plex variety of risks and benefits that are associated with an 17 18 experimental procedure, and it was his state of mind after that 19 long period of time.

20 DR. GLANZ: I think that is right, but I think one of the problems with that interpretation is that the court 22 really doesn't examine Doe in that case. They don't really 23 say what did you know or what did you understand. Although 24 you certainly have to read a case keeping in mind the specific 25 factual situation, the court talked about institutionalization

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1 in very broad terms of institutionalization stripping a per-2 son's capacity to do X, Y and Z. It doesn't say that it stripped John Doe's capacity to do X, Y and Z. The opinion, 3 though -- I don't think the Kaimowitz opinion is a particularly 5 well-written opinion. I mean, there are a lot of things on 6 Constitutional issues that don't really make a lot of sense. 7 The other thing that you have to keep in mind besides the fact that this is dealing with an involuntarily committed 8 mental patient who was institutionalized for 17 years and was probably being held unconstitutionally, and indeed he was re-10 leased before this case was decided, is that it was the lowest 11 12 court in Michigan. It wasn't the Michigan Supreme Court. It was the lowest court in Michigan. The case doesn't have very 13 14 much precedential value. The reason why we use it and the 15 reason why it is used so often is because it is the only thing we have and we have to use it. That has to be kept in mind, 16 17 too.

18 DR. RYAN: Mr. Mangel, please. 19 MR. MANGEL: I would like to follow up on Dr. Jonsen's question. It seems to me there are two ways you can rationalize 20 One is the way that Dr. Jonsen has done it, and that 21 Kaimowitz. 22 is the court seems to be saying prisoners can consent, but 23 they may have somewhat diminished capacity and we are going to 24 look at what is being proposed to be done to them and see how 25 complex it is or how dangerous it is, and we will allow consent

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1 in one case and not in another; or the court could be saying 2 that prisoners just can't consent, but in some certain cases, 3 like therapeutic research, we are not going to require consent 4 and we are going to allow some kind of substitute consent. 5 That second kind of analysis is one that I would like your 6 thoughts on. Just from a strictly legal point of view, how viable/ you think the distinction/therapeutic_non-therapeutic 7 8 is, how useful is it in the prison setting, and can you extra-9 polate from the other areas where you are dealing with people 10 of diminished capacity, like minors or mental incompetents, 11 where they have made dis-12 tinction between therapeutic and non-therapeutic. 13 DR. GLANZ: Okay. I am not sure that in the prison 14 setting the difference between therapeutic and non-therapeutic 15 research is all that compelling, although I certainly person-16 ally feel more comfortable with therapeutic research. I like 17 the idea that someone will benefit from what is being done to 18 him. I think that if we think that prisoners are adults and 19 they are not incompetent, as children are incompetent and as 20 mental patients may be incompetent, but are not always incom-21 petent, and we let them decide what can be done to them for 22 therapeutic reasons, we let them assess the risks and benefits 23 of what will be done to them for therapeutic reasons and then 24 they make a decision, I am not sure that their ability to

assess risks and benefits is decreased if it is non-therapeutic

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1 In other words, the risks would be the same, the benefits might be hen-existent, but at least they will have 2 an understanding that they are non-existent and then they could 3 decide whether or not to take that risk. Unlike children and incompetent people, mental patients who are deemed to be in-5 competent, I think we could say that prisoners should be 6 allowed ordinarily to consent to their own medical care and 7 invasions into their bodies. The problem with children and 8 incompetents, of proxy consents, what can someone else decide Ò to do to this person which isn't for their benefit. I don't 10 think that is a problem in the prison situation, though. So 11 again, though personally I feel more comfortable with thera-12 peutic procedures, as a lawyer, in the prison setting I am not 1.3 sure that it makes that much difference. Again, I wouldn't 14 15 make a pat statement one way or the other on it. MR. MANGEL: Let me just turn the question around 16 a little bit. Supposing you start from the assumption that 17 prisoners, because of the inherent coerciveness of the atmos-18 phere in which they operate, cannot give consent in the legal 19 sense. Aren't you then by logic really forced to fall back on 20 that distinction, because otherwise you would not allow them 21 even to participate in therapeutic research, and maybe not even 22 to accept therapeutic treatment, because even treatment requires 23 the giving of consent or some form of substitute consent. 24 DR. GLANZ: I think that is right. I think that if

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1 you decide, if you decide that prisoners can't consent because 2 of the institutionalization or their incarceration, to get 3 away from the concept of institutionalization, then I think 4 that the distinction should be drawn so that you don't deprive 5 prisoners of treatment that might be beneficial to them. I 6 am not sure whether you would say that we are only going to 7 allow them to do that because their capacity to consent is 8 diminished. That is why we will only allow them to consent to 9 therapeutic research. But what you then go on and say is that 10 since their capacity is diminished we have to get the consent 11 of somebody else anyway, and should we go to court as we do 12 with children or incompetents. 13 DR. RYAN: Dr. Lebacqz? 14 DR. LEBACQZ: Yes, I have a question. I want to be 15 sure that I un "stood correctly something that you said 16 earlier this morning, and then if I did I have a question that 17 follows on that. It was on the question of the court's atti-18 tude toward behavior modification programs, or what might 19 loosely be called experimental techniques in behavior modifi-20 cation, although I am not sure we could always apply the term 21 "research" to that. I think that I heard you say that by and 22 large the courts have tended to view behavior modification as 23 therapeutic for the individual and that their attitudes and 24 approaches to it then perhaps have been in some way influenced 25 by that favorable view of it. Was that correct?

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DR. GLANZ: Yes. That, by the way, is my reading 2 into it. They haven't said specifically that it is therapeutid. 3 DR. LEBACQZ: Right. That is a position with which I have some difficulty myself. It is not clear to me that be-4 5 havior modification is ever therapeutic for the individual, and I wonder if you can shed some light on that, either in 5 terms of your own personal opinion or in terms of your work in 7 the law as to what kinds of standards there are for things to 8 9 be therapeutic for someone and whether behavior modification 10 ought to be looked at in that way or not. DR. GLANZ: The reason why I said that is I am dif-11 ferentiating it from the pharmaceutical type of research that 12 is done. Assuming the pharmaceutical research is done succes-13 fully, what happens is we now have a drug which we know works 14 15 or it doesn't work. One way or the other we know something about the drug. The prisoner isn't changed one way or the other. 16 17 With behavior modification programs, assuming it is experimental and assuming we are trying to see if it does change behavior 18 in a positive way -- take the case of treating pedophiles, for 19 instance -- if that is successful and it is done, it is done 20 21 and it is successful and we get the consent of the person, then that person will no longer be a pedophile. I think the court 22 would say that that is good, that that is good for the person 23 and the person is better off for having gone through that pro-24 ĝ 25 gram. That is why I approached it as being therapeutic.

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DR. LEBACQUZ: Have the courts at all required that 2 the individual make the request for that kind of intervention? 3 DR. GLANZ: I don't believe that is the case, no. I 4 think the intervention is discussed -- well, in these cases 5 it was more than discussed with the person, but I think in 6 terms of consent it would be discussed and it would be made 7 known that that sort of thing exists. 8 DR. RYAN: John Irwin and Stephen Toulmin, please. 9 DR. IRWIN: Let me suggest a way out of that apparent 10 contradiction between their attitude in case of experiment as 11 opposed to treatment. It seems to me when they are dealing 12 with a subject for the purposes of experimentation, they are 13 treating them as a subject and asking them to be an object of 14 this experimentation, but when a penal system is dealing with 15 a person for the purposes of treatment, that is part of their mandate to treat them, with or without their consent. 16 The courts have ruled in this direction quite a few times. In 17 18 other words, as they are sent to prison for punishment, they 19 are also sent to prison for treatment. It is not to their discretion. Their consent is not required. Therefore that 2Ů removes this requirement that they be in a certain mental state 21 22 where they can -- in fact, they do force, and the courts have 23 upheld their right to force treatment on people of a variety of 24 types, and I can think of only a few cases where they have gone in the other direction, but the rulings on the indeterminat 25

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sentence system were clearly forced treatment, and so on. The Supreme Court has consistently held that they have that as part 2 of its mandate to rehabilitate, and manipulating sentences for 3 this purpose is proper, therefore. DR. GLANZ: Well, the issue, though, becomes what are the limits of that? In other words, clearly if a correctional institution said we think if you hang prisoners by 7 8 their thumbs for three days in cold weather that that will held them, that wouldn't be permitted. There are still restrictions 9 on what can be done to people, especially in terms of invading 10 their bodies, which is different than some other forms of 11 12 punishment, such as solitary and that sort of thing, although the courts are now coming to the opinion that when you are 13 punishing somebody, if you take away good time privileges, for 14 instance, because of something they have done, you don't have 15 to get their consent but you at least have to give them a 16 17 hearing of some sort.

18 I think more and more, prisoners are getting more rights in that area, concerning what can be done to them, al-19 though I think you are right in your interpretation that courts 20 in the past have said that you can do pretty much what you want 21 22 to prisoners. In the paper I sent out there was a line of 23 cases from the Eighth Circuit, six or seven cases that all look 24 like they say the same thing, and they do, but they were all 25 written by one judge. When you look outside that, though, there

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seems to be some diversity of opinion, but it is a difficult 1 area. I think it is an area that is changing very rapidly 2 right now. 3

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DR. RYAN: Dr. Toulmin, please.

DR. TOULMIN: Could I just follow this up a little 5 further? It is clear that in many of the cases you cited the 6 question at issue is how the courts draw the line between 7 humane and inhumane treatment. In, for instance, the case of 8 aversive drug therapy, the use of aversive drugs for improving Q 10 behavior, the complaint is not that it is treatment, but that it is inhumane treatment. But it seems to me that we are hav-11 ing a bit of trouble here of the kind we have had in other 12 areas, which is/the word "treatment" is in fact much broader 13 in its application than the phrase "medical treatment," and 14 therefore one feels very uncomfortable when in this case we 15 slide from the word "treatment" to the word "therapy," or the 16 word "therapeutic" and this family of terms. It is clear that 17 there is just as strong an argument for talking about certain 18 kinds of behavior modification as re-education, or, the natural 19 word in the prison context is rehabilitation. 20

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Now, I want to ask you, is there any line of cases 21 that allows this to draw a line, draw a boundary, in legal terms, between what constitutes medical treatment and what con-23 stitutes re-education or rehabilitation? It does seem to me 24 that when we slide from the pharmaceutical kind of research to 25

1 allegedly therapeutic behavior mod, that there is a terrible 2 trap that we can fall into if we assume that the treatment in-3 volved in behavior mod procedures is indeed still sufficiently 4 comparable for legal purposes with medical treatment rather 5 than being a kind of re-education procedure. 6 DR. GLANZ: I really don't know off-hand of cases 7 that say some X is medical treatment, although you may not 8 think that it is. I think that in the behavior modification 9 programs, I think the behavior modifiers would say it is a 10 form of re-education. I don't think that they would even say 11 it is a form of medical treatment, but that it is a form of 12 education, of learning to respond/different ways to old stimu-13 li. But again, why would that distinction be important from 14 your point of view? 15 DR. TOULMIN: The question of the circumstances in 16 which and the conditions on which one is required to give or 17 entitled to withhold consent in the area of education is quite 18 a different question from the question that arises in the case

of medical treatment.

DR. GLANZ: I see.

21 DR. TOULMIN: We are required to consent to education, 22 and parents are deprived of the right to withhold consent for 23 their children to be educated. This is a much more complex 24 situation.

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DR. GLANZ: Okay, I think I understand.

DR. TOULMIN: The obligation to enter into educational 2 activities is much stronger in the eyes of the law, as well as 3 in other ways, than the obligation to consent to medical treat 3 4 ment. 5 DR. GLANZ: I think I understand the guestion. 5 6 DR. TOULMIN: I am not arguing anything. I am in-6 7 terested in the distinction. 8 DR. GLANZ: Sure. I think that the question is 8 9 clear in my mind now, and what I would do is to draw the dis-9 10 tinction between the Clonce v. Richardson case and the Knecht 10 it is a whole different set of problems. 11 v. Gillman and Mackey and Procunier cases, where in Knecht, 11 DR. RYAN: Dr. Cooke, please. 12 they didn't do much to those people. They took away certain -12 13 I mean in Clonce -- they took away certain privileges but they 13 14 didn't give them Apomorphine, they didn't give them Anectine, 14 15 they weren't making them throw up, they weren't causing their 15 16 breathing to cease. What they were saying is that you can't 16 17 read certain books, you can't get certain mail, you can't do 17 18 those types of things. As a result of that the court -- well, 18 very minor part of such research. 19 the court never got to talk about the consent issue, and it 19 DR. GLANZ: Right, I agree. 20 didn't seem to think that it needed to. What it said is that 20 21 you have to give them certain rights, due process rights, be-21 22 fore you put them in this sort of institution and this program, 22 DR. RYAN: Dr. Seldin, please. 23 but you don't necessarily have to get their consent, although 23 gg 24 we don't want to talk about the consent issue. 24 BOW 25 If you look at the Knecht case and the Procunier

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case, though, where you are giving people injections of drugs which could be dangerous and cause great discomfort, then the courts talk about consent. I think you can draw distinction between giving someone drugs or invading their physical person and re-educating them, putting them in a classroom. I think if a prison said you had to go take math classes for an hour a day, that the courts wouldn't get into too many due process problems or informed consent problems, but if they say you will have your shot of Anectine once a day, which is invasive, then

DR. COOKE: It is a minor matter, but I think it is worth correcting the record and correcting your own misconceptions if what your statement is represents your thinking, and that is your statement that biomedical research was directed at ascertainment of efficacy of treatment. I would like to point out that prisoner research on efficacy of treatment is very,

DR. COOKE: I think that is important because those studies are toxicity studies, metabolism drugs and so forth.

DR. SELDIN: This point that has been raised about behavior modification has to be seen, to my mind, in the light of a sort of public outcry out of a notion that behavior is

being modified in some such way as to change people so as to 2 make them passive, so as to sterilize them, let us say, from radical ideas, so as to make them conform to certain models of behavior, which might make them quiescent, to be sure, but not necessarily more human, in some sense of the term.

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6 The analogy from a mathematics class as a form of 7 education is really not very helpful to my mind. What is 8 really concerned is the other end of the spectrum. When is 9 behavior modification an illegitimate intrusion on certain 10 rights and prerogatives, certain humane activity, which are, 11 let us say, unpleasant and unattractive but nevertheless quite 12 legitimate? I think this kind of concern, which is very wide-13 spread and which has deep roots in problems not too far removed 14 in Europe and elsewhere, has not been addressed in any legiti-15 mate way. I think that the Commission is currently formulating 16 or has formulated a position paper on the boundary rules -- is 17 that not right -- between behavioral modification and research 18 and biomedical research. At least it is supposed to be. What 19 are you shaking your head for?

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20 DR. RYAN: Well, let's not bring that up and --DR. SELDIN: Well, but I think this is a very important point, because I do think, on the one hand, that the real problem does not lie in distinguishing behavior modification and a class of mathematics. I think that behavior modification 25 is a form of disciplining an individual in a way which may be socially unattractive. It is a very critical problem and it

is not merely a medical problem in a narrow sense of the term. 1 Now, how to evaluate this, how to distinguish this form of 2 behavior modification and that form of behavior modification, 3 and this is a medical experiment that is not going to be solved 4 by the distinction between Apomorphine, let us say, as a means 5 of internal invasion, and some other coercive device which is 6 so to speak, a modification of the environment and which would 7 qualify it as behavior modification. 8 DR. GLANZ: So you are saying there are problems of 9 not using invasive techniques but other techniques that are 10 more subtle. 11 DR. SELDIN: That may be much more important. 12 DR. GLANZ: Which may be more important from what 13 point of view? That they are more effective or that they are 14 DR. SELDIN: From the point of view that they alter 15 subtly certain kinds of behavioral characteristics of people, 16 which don't really represent a medical intrusion. They repre-17 sent something like making them more malleable or making them 18 more pleasant or making them less abrasive or less radical, or 19 20 whatever you will. DR. GLANZ: But I think you could start off by saying 21 that the prison environment itself is a behavior modifying 22 23 environment. 2 24

DR. SELDIN: Fine. We accept that as a boundary rule, but behavior modification as a specific educational tool, ž 25

we will say, is a much more specific thing. That can be de-1 2 lineated behavioristically. One doesn't have to get so ela-3 borately theoretical about that. Behavior modification, we 4 understand what that means. We understand this is a specific 5 manipulation of the environment, generally, for the purpose of 6 altering certain types of behavior.

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DR. GLANZ: Okay.

8 DR. SELDIN: I am trying to say that the boundary 9 rules between the legitimacy of this kind of therapy and its, let us say, illegitimacy -- if you want to call it education 10 11 you don't solve the issue of this sort of problem anyway --12 have not been drawn. But it is a very serious problem, in my 13 mind.

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DR. RYAN: David Louisell, please.

15 DR. LOUISELL: From your position, I derive the conclusion, among others, that we have got to be very careful 16 17 about giving too much significance to labeling, for example 18 therapy and non-therapy. Let us take specifically psychosurges 19 Suppose it is the unanimous opinion of the psychiatric compe-20 tence at a given prison, and also the other medical judgment 21 there, that psychosurgery is very desirable treatment for this 22 particular violent prisoner. Now, collaterally, of course, 23 there would be some investigative and experimental value in the performance of the psychosurgery. What would your attitude 24 25 be? Wouldn't the prisoner have a clear right to object to the

performance of that psychosurgery? 1 2 DR. GLANZ: I would certainly agree with that -- to 3 object to it -- sure.

4 DR. LOUISELL: And to prevail in his objection that 5 there shouldn't be this psychosurgery. 6 DR. GLANZ: Absolutely. 7 DR.LOUISELL: Now, how far can you go along lines of 8 less dramatic significance in psychosurgery, for example the 9 use of various drugs; where is it possible as a general matter definition to say where the state's power ends to impose on 10 11 this prisoner its judgment of desirable treatment, whether 12 this be in the name of experimentation or therapy? Are you 13 able to do any generalizing?

14 DR. GLANZ: I don't think I could do generalizing. 15 It is always the hardest part of a project of this nature, 16 but the approach that I would take is that generally, unless 17 you can come up with a compelling reason for doing it you 18 shouldn't invade a prisoner's body with drugs or electrodes 19 or something like that until you can come up with a fairly 20 compelling reason for doing it.

21 Now, one one case that I have talked about, the 22 Reynolds case, for instance, a hemorrhoidectomy was done 23 without the consent of the patient and that was found to be 24 cruel and unusual treatment, or could be. It was sent back a 25 for trial. That is not for behavior modification purposes or

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anything like that, but they were invading the body of this person. They were doing something to this person that caused 2 discomfort. It would be a battery, ordinarily, if one were З free living and one didn't consent. The person has to be 4 allowed to consent to that sort of thing. 5

Now, the question that was raised here, where you 6 are not dealing with invasive drugs and you don't touch the 7 body I think is a much subtler question in terms of trying to 8 figure out guidelines, what are you actually trying to do to 9 this person. I would feel comfortable, I think, in absence of 10 a compelling reason, not to invade the body of the prisoner 11 with drugs or surgery or something like that without his con-12 13 sent.

DR. LOUISELL: And you would say that however strong 14 the alleged reasons of the state might be to perform that 15 body invasion. 16

DR. GLANZ: However strong?

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DR. LOUISELL: I mean, however cogent the reasoning 18 of the medical authorities of that particular prison might be 19 in the direction of giving that kind of medical treatment, 20 still if it is this kind of invasion of the body that you are 21 talking about, the prisoner would prevail. 22

DR. GLANZ: I hate to talk about absolutes, that is 23 for sure. I would never say that that could never occur, but 24 a 25 I think that if you look at free living persons and a physicia

says to them, all physicians say to them, "Listen, I really 2 think you should have this procedure, it is good for you, you 3 will live a lot longer, you will be a lot healthier and happier," if the person says no, we don't expect that person to 5 undergo that procedure, and I am not sure why in the prison 6 situation we would expect the outcome of that to be different. 7 DR. RYAN: Okay, we want to bring this discussion to 8 an end, now, if we can. Dr. Lebacqz, did you have a final 9 point?

10 DR. LEBACQ2: I just wanted to once again very ון quickly make sure that I am clear on what the law does and 12 doesn't help us with in this whole arena. I understand you 13 to say that if we are talking about invasions of the body, 14 that there is some legal material that tells us that there are 15 certain things that we cannot do without someone's consent. 16 When we talk about behavior modification, however, we are 17 often talking not about invading the body but about changing 18 the environment, as you just noted. I understand that there 19 is some legal material that sets some limits on what we can do 20 toward changing the environment of someone who is in a penal 21 institution, who is incarcerated, but I am still seeking if 22 there are any legal guidelines for guidelines for when those 23 kinds of environmental invasions are not acceptable and when 24 they would be considered acceptable to do with a person's a 25 consent and when they would be considered acceptable to do

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without someone's consent. Is there any help for us?

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2 DR. GLANZ: It is a very difficult question, only 3 because there isn't law on it. Most of the cases that deal 4 with this problem deal with the case of cruel and unusual pun-5 ishment under the Eighth Amendment to the Constitution, and 6 it is a very vague kind of test. The courts kind of ask does 7 this shock the conscience of the court, this kind of thing, 8 and it often takes a lot to shock the conscience of a court. 9 What the courts really do is they look at the situation in a 10 very human sort of way. That is the interesting thing about 11 the Knecht v. Gillman case, which deals with the vomiting ex-12 periments, where a person vomits for an hour after injection -13 15 minutes to an hour after injection with Apomorphine. The 14 court says, as we all know from our own unfortunate experiences 15 and you can see that the court is feeling for this person, 16 saying, "I wouldn't want to throw up for an hour in front of 17 other people," and I think that is the way the courts are 18 really looking at this, like, "I wouldn't want to suffocate," 19 and that is where they are coming from. Because of that, it 20 is very vaque.

21 They are not saying that this does X, Y, and Z and 22 therefore we don't like it. They are really applying personal 23 values to it, and it makes it very difficult to draw a line as 24 a result of that.

DR. LEBACQZ: So we are not going to get much help

in terms of finding principles on which we can make distinctions by looking at the legal material. DR. GLANZ: Well, from my point of view, though, I 3 am dealing with this from the point of view of informed consend, 4 and right now, forgetting about the Kamowitz case for the mo-5 ment, which is really a very extreme case, and perhaps not a 6 very well-decided case, but excluding that case for the moment, 7 the point that I would make is that if you have adequate safe-8 guards you can do an awful lot, I think, to a prison population 9 as long as they consent and that there are certain safeguards 10 built into it. I think that one of the Commission's duties is 11 to figure out what those safeguards should be and how that con-12 sent is obtained, and that is a point I would take, that I don't 13 even think we would want to do very much to prisoners, now 14 getting into policy, which I promised not to talk about, without 15 obtaining their consent. That was the issue that I was dealing 16 17 with.

18 Thank you very much. DR, RYAN: 19 Thank you. DR. GLANZ: DR. RYAN: What I would like to do now is try to go 20 to the report from the Survey Research Center of Michigan. I 21 believe Dr. Tannenbaum is with us and is going to give us a fuod 22 report. It is under Tab 16. I underestimated the time it would 23 take to go over these things. I want to allocate an hour and 24 would hope we could finish before lunch if we go for the time. ŝ 25

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I am not sure the Commission members have seen this previously 2 This has just come to us, and I think it might be helpful if you would give us an overview and point out for us where you have specific facts. We were wrestling this morning about 5 race ratios. Tell us what institutions you have surveyed and 6 point out to us where you have facts that have been validated, 7 please.

8 DR. TANNENBAUM: Let me state at the outset in 9 response to what you just suggested, Dr. Ryan, that one thing 10 I cannot do is mention the specific institutions. I will pro-11 vide data about a set of institutions. There are five alto-12 gether in this particular study. But I cannot mention names 13 of institutions or names of persons.

14 We spoke to persons who are associated with the 15 research process in five state prisons, associated in different 16 ways, persons who play different roles in the research process 17 We spoke to chairmen of review committees connected with re-18 search at each of these places. We conducted interviews with 19 41 principal investigators who are conducting research at 20 these places. I might interject here a technical note which 21 some of you may be interested in, namely that the unit of anal 22 ysis which we are employing in this study is the research pro-23 ject. That is, we are interested in surveying projects. We want to know how many there are, we want to know what the cha-24 25 racter of the projects are, we want to know the reactions of

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1 subjects in these projects, and most of the numbers that I 2 provide apply to the project as a unit, so that if a principal 3 investigator, a given individual is associated with two pro-4 jects and we talked to him about those two, we present that a 5 two interviews. I want you to keep that in mind. 6 We conducted 181 interviews with subjects in four of 7 the five prisons. We were not able, due to the limitations of 8 time, to get the approval necessary to enter the fifth prison, 9 so insofar as subjects are concerned, we are talking about four 10 of the five prisons. In addition to that, for reasons that I 11 will explain later we added to the initial study design 45 pri+ 12 soners who are not subjects. We felt it important, necessary, 13 in fact, to make a comparison between those who are subjects 14 and those who are not subjects. In two prisons we were able 15 to include in our survey prisoners who were not subjects. 16 Now, let me try to review briefly what I think you

17 will find in the report when you have time to go through it in 18 detail. No two prisons are alike insofar as the review pro-19 cess is concerned. In some, institutional review boards with 20 general assurances play an important role. In others, review 21 committees that are appointed by the Department of Corrections 22 or by prison authorities or by university officials may play 23 an important role. Drug companies in some cases have review 24 committees which are part of the process. In addition, there ā 25 are biomedical and legal consultants, and in a few cases,

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prison representatives who play roles on some of these commit-2 tees. In all cases, the process involves a number of stages 3 that protocols pass through from one committee to another, but as I said before, the procedures and the processes are different from one place to another. 5

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Now, insofar as the principal investigators are con-6 7 cerned, we got information from them about the nature of the 8 research that they are doing, and the work that we were able 9 to study through the principal investigators is predominantly, if not exclusively, pharmaceutical research involving, to a 10 11 large measure, Phase I testing. Most of the studies involve 12 some kind of oral administration of a drug or chemical. Blood and urine samples are analyzed. Few, very few, are specifically 13 14 intended to benefit the subjects medically, although some in 15 the opinion of researchers do have such benefit.

16 Also, researchers point out, there are some risks, 17 although the probability of serious risk, according to the in-18 vestigators, is very low or non-existent. For those of you who would like to see the basis for that statement, you might look 19 at page 19, Table 6 in the report. There you see the data 20 that is based on the responses of the principal investigators 21 22 to the question dealing with risk. Along the top of the page 23 you see the scale which they used to estimate risk and see different kinds of risks presented along the vertical axis, so 24 that the probability of temporary or minor psychological stress

or discomfort due to the research is estimated to involve no risk of that type by 8 percent, and very low risk of that type by 82 percent of the investigators and so on. 3 All of the investigators ---4 DR. COOKE: Before you go on, could we ask you more 5 about this table? Are these judgments made by the investigators? Are they retrospective data collected in terms of outcome 7 and so forth? Could you tell us about that? 8 DR. TANNENBAUM: Yes. These are estimates made by 9 the investigators. 10 11 DR. COOKE: No one has taken 10,000 cases that have 12 been passed through particular institutions and done statistical analyses of the harm consequences. 13 DR. TANNENBAUM: Not to my knowledge. 14 DR. COOKE: Is there such data available anywhere? 15 16 DR. TANNENBAUM: Not to my knowledge. There may be. Dr. Cooke, we did ask investigators as a follow up to this 17 18 question whether in their experience there were serious harmful effects, and one investigator said that there were some 19 temporary effects that were serious, but that was the only case 20 reported to us by investigators. We spoke to prisoners about 21 22 this subject, and if you don't mind, when we get to the prisoner 23 phase I will get into this again. 24 DR. JONSEN: May I ask also about the table? Are 25 these investigators being asked each about their own project, or is it a panel of investigators looking at the variety of

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	1	projects?		
	2	DR. TANNENBAUM: Each is being asked about his own.		I might say that all of t
	3	We did ask the review board members about what you might call	2	that there are procedure.
	4	a panel of projects, the projects that passed through, and I	3	Some narmitur errect.
	5	think it is fair to say that their estimate with regard to	4	we obtained the
	6	risk corresponds pretty much to that of the principal investi-	5	jects and we did a conter
	7	gators.	6	in the report you will se
	8	DR. RYAN: Bob, do you want to ask a clarifying ques	7	I will give you some of
	9	tion?	8	to have at this moment.
	10	DR. LEVINE: Yes, about a point made a couple of	9	procedures. Some describ
	11	minutes ago. You said a great majority of studies on drugs	10	describe them in detail,
	12		11	and provide some descript
		were Phase I studies. The data, I believe, are in Table 2.	12	the purpose of the exper:
	13	Are these data you say 80 percent are Phase I, but it is	13	and some provide long lis
	14	not clear whether it is 80 percent of investigators are in-	14	subjects can withdraw.
	15	volved in that work, 80 percent of protocols, or 80 percent	15	Now, if you was
	16	of the subjects.	16	more concrete and help yo
	17	DR. TANNENBAUM: It is 80 percent of the protocols.	17	have just made, you might
	18	DR. LEVINE: Do you have any idea as to what percen-	18	where the various aspect:
	19	tage of all subjects were involved in Phase I as opposed to	19	the review board, are cod
	20	later phase drug research?	20	with which they occur, so
	21	DR. TANNENBAUM: We can get that. We have a basis	21	the very first item there
	22	for answering that question, but we haven't done that particu-	22 Company	cases and a detailed des
ortina C	23	lar analysis, since we can associate each subject with each		of the cases.
Bowers Reporting Company	24	project and we know what phase the project is, and we can	s zborting 24	
RO B	25	therefore answer your question in due time. Okay?	¹³ 25	

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the principal investigators indicate es to treat subjects in the event of

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the consent forms for each of the protent analysis of those consent forms, and see a more detailed description of that the points that I think you might want All of the consent forms describe the the procedures very briefly, some , but all of them do make some mention ption of procedures. Almost all describe eriment. About 85 percent mention risks ists of risk; 95 percent state that the

you see the basis for the statements I you see the basis for the statements I ght take a look at page 24, for example, ets, various topics that are mentioned in coded here according to the frequency so that you see "Statement of Procedures," ere, is mentioned in 32 percent of the escription in 68 -- the other 68 percent

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on analysis of the reading level of these bund that the reading level is very

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1	difficult. We think, and we want to do more analysis on this
2	to make statements that are a bit more definitive, but at any
3	rate, we think at this point that it is not simply due to
4	medical terminology, that it has to do with the sentence struc
5	ture and the choice of words, but not necessarily the medical
6	terms and the technical jargon that these investigators are
7	using. There is a very small correlation, for example, betwee
8	reading level difficulty and the frequency of medical terms,
9	so these investigators apparently are using a mode of descrip-
10	tion that is somewhat complex, and therefore the consent form
11	itself is rather difficult to understand, although I should
12	mention that the consent form is only one of the procedures
13	that investigators tell us they employ in communicating or
14	describing the research to subjects. There is also an oral
15	presentation by them in all cases, according to our respondents
16	DR. COOKE: Would you say they are written as though
17	they had been written by an ethicist for this Commission?
18	DR. TOULMIN: Not all ethicists write alike.
19	DR. RYAN: Dr. Tannenbaum?
20	DR. TANNENBAUM: We present a couple examples, Dr.
21	Cooke, for your benefit and for the benefit of some of the
22	ethicists on page 31, if you want to take a quick look at that
23	You can see what and I might add here that we have substi-
24	tuted the name of the chemical there. That is not the name of the chemical there is not the name of the chemical that was stated in the original consent form. We
25	the chemical that was stated in the original consent form. We

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code that as reading level, and there is a score you can see 1 associated with that, 13.9, very difficult. By way of con-2 trast but not too much of a contrast, the next example has a 3 score of 54.7, which we code as fairly difficult, and we have 4 a formula for coding. I don't know whether the ethicists do 5 any better than the doctors and lawyers and others on this. 6 DR. COOKE: We have heard about one. 7 DR. TANNENBAUM: Okay? 8 9 SPEAKER: Objection. DR. TANNENBAUM: Now, one correlation that we find 10 a bit intriguing, and I want to forewarn you that this analysis 11 is just beginning, now, and we would want to examine these 12 data in more detail before we felt confident about making 13 statements that have important implications. But let me just 14 point this out as a correlation that I think is of some in-15 terest and may have practical implications. There is a corre-16 lation of negative 63, which is a fairly substantial correla-17 tion, between the risk level of the project as is estimated by 18 the investigator, the amount of risk as estimated by the in-19 vestigator, and the reading ease. In other words, the more 20 risk, the more difficult it is to understand, and we want to 21 go into this in a little more detail. 22 There are a number of speculations we can offer and 23 I am sure you have additional ones, but one obvious specula-24 tion is that those that involve somewhat more risk state a 25

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larger number of symptoms that might be stated in technical 2 terms or in complex terms, and for that reason it becomes more difficult to understand those particular consent forms.

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4 Now, let me say something about the information we obtained from the subjects themselves. These are subjects who 6 have participated in research sometime since July 1974. Sub-7 jects who were in research prior to that date are not in our 8 survey. The subjects are generally supportive of biomedical 9 research in prisons. We find a near consensus in all four 10 prisons with respect to the attitudes of subjects as conveyed 11 to us about research in prisons. These subjects say, almost 12 universally, that the research before they participated in it 13 was explained to them so it was understandable, and you can 14 see the data that refers to that point on page 41.

15 Let me read the question. This is the question we 16 asked in the interview. "When you agreed to participate, did 17 you feel that the information that was given to you was clear 18 and understandable?" Ninety-nine percent say yes. On page 43 19 you see data that refers to the extent to which the data was 20 correct and accurate in their opinion, now that they have been 21 through the experiment, 97 percent saying yes. One subject 22 whom I interviewed personally and who answered no to that ques 23 tion told me that there was a greater number of times that 24 blood was drawn than he had originally expected.

The subjects also indicate that researchers are

willing to answer their questions, and you see that data presented on page 44, approximately. I would say it is better 2 than approximately. Ninety-nine percent say that researchers were willing to answer their questions. On page 55 you see the extent to which subjects themselves feel that their parti-5 cipation was voluntary. If you look at the bottom of that 6 page, Table 31, "When you agreed to participate, did you feel that it was a purely voluntary matter; that is, did you feel free to refuse?" Ninety-five percent answered affirmatively 9 to that. Those who answered negatively, we followed that up, 10 and we found that the reason that they did not feel that it was 11 voluntary is that they saw or felt that they would be withdrawn 12 13 from the subject pool and therefore for that reason they didn't 14 feel that it was voluntary. 15 DR. RYAN: Dr. Jonsen. 16 DR. JONSEN: Would you clarify that? Did all of 17 the 5 percent answer that way? 18 DR. TANNENBAUM: The answer is yes to that. By the 19 way, one person did not answer that question. We have only 20 180 interviews, as you can see. Now, 3 percent of those who 21 did did answer, and that turns out to be six subjects, and 22 remember I am using the word "subject" in the sense that I de-23 fined it earlier, in that technical sense, as persons playing 24 roles on projects, and one person might be two subjects if he 25 was on two projects. Okay?

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	1	DR. JONSEN: So this very small and I am not try-	1	DR. TANNENBAUM:
	2	ing to draw any great conclusion from this they volunteered	2	two cases may I qualify
	3	the answer that if they refused to participate in this project	3	"think" so, and if you are
	4	they feared that they would be removed from the volunteer pool	4	want to check it to be abso
	5	DR. TANNENBAUM: Yes, as I recall it, from other	5	answer is yes. In two othe
	6	projects in the future, and there may have been a time asso-	6	the specific risks, were in
	7	ciated with that.	7	and this may be an irony of
	8	DR. RYAN: I think this was indicated to us on some	8	attempted to be comprehensi
	9	of our visits as well.	9	and these were among that 1
	10	DR. TANNENBAUM: This occurred at one place. Thirty	10	
	11	three percent of our subject respondents expected a risk when	11	tioned earlier, that these
	12	they signed on for this project. Some of them, however, ex-	12	and difficult to understand
	13	perienced difficulties that they didn't fully anticipate. We	13	
	14	spoke to several such persons, six, I believe, such persons.	14	
	15	These unanticipated difficulties included nausea, allergic	15	might occur and that these
	16	reaction, and in one case, violent behavior, as a result of	16	some examples were provided
	17	the administration of a drug. We examined the consent forms	17 17	were provided were not the
	18	that were connected with each of these cases to see what the	18	symptom that this subject s
	19	consent forms said about these risks which the subjects said	19	anticipate this specific co
	20	they did not anticipate, and we found that in each case there	20	DR. KING: The on
oorting Company	21	was a mention in some way of these particular contingencies,	21	vior, what did that consent
	22	these particular risks. In two cases the risk was very clearly		sure I get that clearly in a
	23	stated and very explicitly indicated.	E O O	reaction.
	24	DR. LOUISELL: Was the incidence of violent behavior	Builtoday 24	
BOWEIS	25	toward another person?	sumog 25	DR. TANNENBAUM:
	н.			here, but I believe that the

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Yes, I believe it was, yes. In that? I underline the word I interested in that question I would olutely sure, but I think that the er cases the specific possibilities, n fact mentioned in a long list, f it. Presumably the investigator ive about the risks, had a long list, long list and apparently it got lost, is is associated with what I menconsent forms are difficult to read

one other case -- on that consent that "various allergic reactions" reactions might be serious, and d. But the specific examples that specific manifestation, the specific suffered, and therefore he did not ontingency.

e with respect to the violent beha-: form state? I just want to make my mind, where there was a violent

I don't have the specific wording is was anticipated. It seems ironic

to me, as a layman, to learn, as I am in this project, that tranquilizers sometimes have the effect of creating violence in people.

DR. KING: Could I ask a further question? Did you -5 follow up -- and I don't know if this is a part of your study 6 that one instance because there was a possibility of some forms 7 of mild violent behavior? Were there any precautions taken or 8 was there anything said on the consent form that would suggest 9 certain types of precautions would be taken to make sure the 10 prisoner wasn't dangerous to himself or to others, or was it 11 just stated and then there was a reaction? I am curious about 12 how that got handled in the research setting, or if that came 13 out in your study.

14 DR. TANNENBAUM: My impression as I recall that case 15 is that the behavior occurred subsequent to the departure of 16 the subject from the research setting, that it happened back 17 in the cell block or someplace outside of that setting.

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DR. RYAN: Barbara Mishkin.

19 MS. MISHKIN: Dovetailing on that, there is one bit 20 of information, back on page 27, which has to do partly with 21 this, which I found very interesting, and that is that none of 22 the consent forms which you examined mentioned any procedure 23 or possibility of compensation for harmful effects, although 24 apparently the PMA study indicates that a lot of the drug com-25 panies doing research have the possibility of doing that, but

it is not apparently relayed to the prisoner subjects. I thought that was very important and I didn't want you to miss 2 that. 3

DR. TANNENBAUM: The fact that it is not mentioned in 4 the consent form does not mean that it is not done, and all of -5 the investigators told us that they have procedures for taking 6 care of or working with the subjects who have experienced that 7 MS. MISHKIN: The question is whether the subjects 8 know of that availability. Q DR. TANNENBAUM: Some of them do, and it is conveyed 10 to them, not through the consent form, but through --11 MS. MISHKIN: Okay. 12 DR. TANNENBAUM: Subjects offer a number of reasons 13 for their participation, and I think you are more or less fa-14 miliar with this kind of data. I don't know whether I would 15 want to use the word "motivation," here, but at any rate these 16 are reasons that subjects offer when we ask them what are the 17 main reasons you participated in the research. Page 47 outlines 18 those. This is coded on the basis of their words, and I guess 19 it doesn't surprise you to find that 70 percent of the subjects 20 mentioned money. These percentages, by the way, will add up 21 to more than 100 percent, since subjects can offer more than 22 one reason. Prisoners, like anybody else, usually have more 23 than one reason for doing what they are doing. I think it might 24 be interesting to mention, interesting to you to know, that a 25

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1 the investigators themselves are reasonably realistic about 2 this in the sense that when we ask investigators why they think 3 that subjects choose to participate, a very large percent, 4 about 80 percent, indicate that money is the primary motivation 5 there. While we are talking about money, you might want to 6 look at page 17, which shows the distribution of pay.

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7 I am interested in this for more than the substantive 8 reasons, and perhaps I can induce you to be interested in it_ 9 for the same reason that I am, in addition to your own reasons 10 namely, that it has methodological implications, since we have 11 in this table the reports of subjects themselves and the re-12 ports of principal investigators. The two columns show the 13 distributions as reported to us by these two sets of respondents 14 and I find that the correspondence, under the circumstances, i15 quite remarkable, which suggests to me that the respondents are 16 giving us reasonably good, reasonably accurate data and that 17 our sampling procedures are working appropriately. We are 18 getting at a good representation.

19 There are reasons why we would expect discrepancies, 20 by the way, between these two, at least little discrepancies. 21 For example, some investigators are talking about more subjects 22 than other investigators are talking about, so there is a lit-23 tle distortion possible as a result of that. The investiga-24 tors in this particular case come from five prisons, and the 25 subjects come from four. Nonetheless, this seems to be pretty

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standardized, and there you see the distribution of pay. 2 DR. COOKE: Dr. Tannenbaum, may I ask if you inquired 3 as to the method by which the reimbursement was scaled? That 4 is, was it done in terms of inconvenience, time, or risk, or 5 all three?

is in terms of time.

8 DR. COOKE: I think that would be important if it 9 were possible to find out, because I got the impression that 10 sometimes where the risk is greater there is more offered, and 11 other times, if it is a long period and so forth. It would be 12 helpful, I think, because I think it makes a great deal of 13 difference on the compensation issue. 14 DR. TANNENBAUM: Well, we might be able to answer 15 that question when we analyze the data further. 16 DR. STELLAR: It would also be helpful in understand+ 17 ing this table if there were some constant as to the rate of 18 pay for overtime or for time. YOu can't tell from this whether 19 the \$150 came from a long exposure to an experimental procedure 20 and the \$10 for a quick procedure that just took a few minutes 21 and therefore you have no idea of the range of pay per effort 22 expended on the part of the subject. Can you do that? 23 DR. TANNENBAUM: We have information about the dura-24 tion of the project, we have information about the pay assog 25 ciated with that project, and --

DR. TANNENBAUM: I am not sure of that. I think it

DR. STELLAR: It would be helpful to have it on this table if you could.

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DR. TANNENBAUM: Yes, okay. I hear you.

DR. RYAN: Do you want to sort of wrap up a little more, and then we will throw it open for general discussion.

DR. TANNENBAUM: All right. You mentioned race at 6 7 the outset, Ken, and perhaps I should point, since we are very 8 close to that on the report, page 16, you can just flip back to page 16, to it. Again, here we have the distribution of 9 race as presented to us by the research investigators. This is 10 their estimate. Then in the second column we have the percent 11 12 that we were able to obtain through our direct interviews of 13 subjects. Again, you see that the two distributions are remarkably close and the judgments of the investigators seem 14 realistic and the correspondence that we would expect is there 15 DR. KING: Dr. Tannenbaum, do we have the prison 16 17 populations by race of the institutions? I know we must keep the institutions confidential, and I don't know if that would 18 reveal it, but I would like to see this data in comparison 19 to the prison population from which the people were drawn. If 20 to break it down by institution is too revealing, if we could 21 22 have it as a group it would be helpful. Even that amount would 23 be helpful.

DR. TANNENBAUM: We do not have in our file at the moment the data that you are talking about. We do have

information from the group of non-subjects in two prisons, 2 which group, I believe, does represent the larger prison population, and I can give you some information about that. The differences with respect to race, and I am going to include, 5 now, all minorities in one group -- the difference with regard to race is not consistent in these two prisons. It goes one 6 way in one prison and it may go the other way or there is no 7 8 relationship at all in the second prison. Q DR. KING: I think that would be helpful. Any further 10 breakdown about the prison population racial composition as 11 it relates to the participation in research, to the degree it 12 does not violate confidentiality, would be beneficial. 13 DR. TANNENBAUM: Yes. I can give you -- did you 14 want to ask a question? 15 DR. STELLAR: Well, I was going to add that I think 16 it becomes very important to see the individual prisons, not 17 by name of course, but if you could give us prison A, B, C and 18 D, because it is easy for these figures to be washed out by 19 one large prison that goes in one direction, for example. 20 DR. TANNENBAUM: We may not be able to do that without 21 violating confidentiality. 22 DR. KING: That was what I was afraid of.

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DR. KING: That was what I was afraid of. DR. RYAN: Michael, do you want to add to that? MR. YESLEY: Yes. Just as an element of process, Arnie, I wonder if this information could be provided by the

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end of today or by tomorrow morning?

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DR. TANNENBAUM: Which data? If it requires, Mike, 2 going into the prisons to get records, the answer is no. If 3 it implies that we get something from our computer, I would 4 say it may be possible, in principle. Now, there is many a 5 slip twixt the cup and the lip, as you know, but we will make 6 every effort to get the information if it is on our computer. 7 DR. RYAN: Brad, do you have a short question? 8

DR. GRAY: We can bring it up after Dr. Tannenbaum 9 has finished. We do have data in front of -- I think the data 10 on Jessup, Maryland was sent to you in the past 2 weeks, I 11 understand, and I have those data, which have a racial break-12 down on subjects and total populations in that prison, and 13 then there was the data on Southern Michigan State Prison in 14 Jackson, which was put together by staff and which was in front 15 of you in a table this morning. So those are --16

DR. KING: That is not my problem. Let me explain 17 why this is of significance to me. This is the only study that 18 we have that anywhere approaches giving us any basis on which 19 to make decisions. Everything else has been impressions and 20 hearsay and blah, blah, blah, blah. This is the only thing I 21 have seen, and before he even finishes I want to congratulate 22 Dr. Tannenbaum, it is the only thing I have seen so far that 23 begins to give me some facts, and it is in relationship to what 24 he has studied that I need additional facts, and that is why Ia 25

am particularly interested in your study. I think so far that 2 it is outstanding.

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3 DR. STELLAR: Without giving us the specific individual prisons, then, even if uncoded, would it be possible for 4 5 you to answer the kind of question that is being raised in a 6 general analytic way, to give your impression of the data as 7 to when --

8 DR. TANNENBAUM: I am sorry. There is a conversation 9 going on here and I am finding it hard to hear what you are 10 saying.

11 DR. RYAN: Please. 12 DR. STELLAR: I am hopeful that perhaps even if you couldn't give us the individual prisons broken down in a coded 13 14 way, that you might be able to give us an analysis whether the 15 same result applies to the five individual prisons or whether 16 there is a great deal of disparity in the results. 17 DR. RYAN: Do you have any major points you want to 18 make with respect to this, because I am sure people are going 19 to have questions.

20 DR. TANNENBAUM: Yes, I would like to make one other 21 point. It has to do with variance and it has to do with varia-22 tions within prisons. It concerns the non-subject prisoners 23 whom we interviewed. It is among this group that we see less 24 support for research in prisons. Some of these prisoners are 25 opposed to research in prisons, and there is more difference

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	.1	of opinion within this group, that is this group of non-subjec		1	DR. TANNENBAUM: L
	2	more difference of opinion about research in prisons than amon	19	2	briefly, point out that this
	3	the subjects themselves, almost all of whom are unanimous and		3	added along the way, and I w
	A	favorable towards the idea of prisons.		4	We began to recognize as we
	5	This group of non-subjects differs somewhat in edu-		5	were rather homogenous. Mos
	6	cation level, job, whether they hold a job, and the hours		6	thing, and we wondered was t
	7	worked in the prison, from the subjects, and we can get into		7	something wrong with our ins
	8	that in the extent that you are interested. I got the message		8	we spoke to we got the same
	9	Dr. Ryan. I better stop now.		9	to see if there were a contr
	10	DR. RYAN: There is more time. Now I want to open		10	
	11	it up.		10	prisoners in a different cat
	12	DR. TOULMIN: This last point does seem very impor-		12	and that is one of the reason
	13	tan't.	and the second		two prisons of non-subjects.
	14	DR. KING: I would like to hear it.		13	There we did find
	15	DR. RYAN: I am not asking him to stop. I just want		14	prepared to tell us that the
	16	the Commission now to interact and get what you want from Dr.		15	research. As I said before,
	17	Tannenbaum now. Yes?	-	16	of them at least would like
	18	DR. KING: I would like to make a request that he	-	17	is the kind of suggestion th
			-	18	our question about suggestio
	19	continue to discuss specifically what the reactions and the		19	non-subjects are by no means
	20	differences and variations are among non-subject prisoners.		20	subjects. That is, there ar
	21	Some of us have not had a chance to read this report, so we	-	21	a distribution there, and be
Company	22	can't possibly ask him intelligent questions, unless we really	Company	22	tively small number, I am a
2	23	hear a really as complete a report as possible.		00	centages on it. As I mentio
515	24	DR. RYAN: Fine. I am happy then. Please go on.	tis Reporting		after the initial project go
BUN.	25	DR. KING: Thank you, Ken.	Bower	25	There are differen

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ANNENBAUM: Let me by way of background, very out that this is an aspect of the study that we way, and I want to explain why we added it. ognize as we interviewed subjects that the data ogenous. Most subjects were telling us the same ondered was there something wrong with us or

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with our instruments such that no matter whom got the same kind of answer. We therefore wanted were a contrast, to see whether different different category would respond differently, of the reasons why we drew a small sample in

we did find that these prisoners were quite 1 us that they were not enthusiastic about this

said before, some of them were opposed, some t would like to see the research stopped. That suggestion that they would make in response to out suggestions. These attitudes on the part of re by no means shared universally among the nonis, there are differences of opinion. You get

there, and because we are dealing with a relamber, I am a little hisitant to put exact per-As I mentioned, this was a subsequent decision al project got launched.

are differences with regard to what you might

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call the demography of these two groups, the subjects and the 2 non-subjects, and because these differences are consistently 3 in the same direction in both prisons, we get the same direction 4 of differences and the differences seem reasonably sizable, 5 even though I don't want to put percentages on it, I think it is reasonable to state that these differences mean something; 6 7 namely, that the subjects have a somewhat higher level of education, formal education. The subjects are a bit higher in the respect. The subjects are more likely, somewhat more likely 10 to have a job in the prison. For those persons in the prison who do have jobs, the hours worked are likely to be greater for 11 12 the subjects than for the non-subjects.

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The reasons that the subjects give -- pardon me -that the non-subjects give for not participating include that some of them had just not been asked, and that is why they haven't participated, some fear harmful effects, some mistrust research and researchers, some are alienated and disaffected and opposed to the system and this is part of the system; so we get a variety of reasons such as that.

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DR. RYAN: Dr. Lebacqz.

21 DR. LEBACQZ: I also want to thank you for what I 22 consider to be very helpful information. I have not had time 23 yet to read this report in detail, so it could be that the an-24 swer to my question is here and I just haven't seen it yet. 25 I did not see in the latter part of your report any data on subjects who had withdrawn from an experiment during the course of the experiment or the research, so I went looking to see whether indeed subjects knew that the could withdraw, and I find that on page 28 there is at least the indication that 95 percent of the consent forms specifically mentioned that the subjects could withdraw if so desired. I wondered whether you had encountered any subjects who did take advantage of that and withdraw, and if so on what grounds, and how they might have differed from those who did not participate at all or who participated fully.

11 DR. TANNENBAUM: No, I don't believe we have. are / some data on page 22, here, 12 MS. MISHKIN: There 13 that -- the top paragraph on page 22 -- 40 percent of the in-14 vestigators reported that at least one subject withdrew after 15 having begun the experiment, and in these studies they reported 16 that an average of 14 percent of the subjects had dropped out. 17 DR. TANNENBAUM: Yes, but I understood the question 18 was about data from the subjects themselves, but perhaps this 19 goes part of the way, at any rate, to giving you some idea of 20 the magnitude of that process of withdrawal. It comes to us 21 from the principal investigators. 22 DR. RYAN: Does your questionnaire include questions 23 to the investigators as to why people withdrew?

DR. TANNENBAUM: Perhaps Brad Gray can answer that.
 He is the author of the original instrument and he may remember

that better than I.

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2 DR. GRAY: I don't think it does. There may be --3 the interviewers, I think, were instructed to write down when explanations were given, and there may be explanations included 5 in the instruments that could be put together, but I don't ሐ know the extent to which that is true.

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DR. RYAN: Mr. Calhoun, please.

8 MR. CALHOUN: One of the interesting things that I 9 have noticed is that race is important as a very critical 10 variable in terms of looking at who research is done on in 11 prison. My question is is it in terms of your analysis, in 12 terms of the survey that you did, did you look at the socio-13 economic background or status of the prisoners? You suggest 14 that the subject inmates were higher educated, worked more 15 hours, and things like that, and I was wondering is there any 16 differentiation between subjects and non-subjects in terms of 17 their socio-economic background? I think this may have some 18 import in terms of the concept that has been suggested that 19 human subjects should be those who are the most free, and that 20 sort of thing, and what this is implying, that these most free 21 subjects are those most capable or most willing to do research 22 Did you look at any such background data?

23 DR. TANNENBAUM: We have questions dealing with the 24 type of work that the subject did prior to being put into pri-25 son. We do not have information about non-subjects. I don't

think we have information about non-subjects in that respect. We do have education, yes. 2 3 DR. RYAN: Dr. Levine, please. DR. LEVINE: On two of the tables there is informa-5 tion about what sorts of elements of informed consent appear on the consent forms. 6 7 DR. TANNENBAUM: What tables are you referring to? DR. LEVINE: Tables 11 and 14. In each case, in 8 9 each category it specifies whether or not something is mentioned or not mentioned. For example, in Table 14, physical risks, 10 11 and the data always add up to 100 percent. In the footnote you do point out that it might have been useful to relate some 12 elements to particular projects. I think this would be ex-13 tremely important, and when I first read the footnotes I thought 14 it might come in later. But the fact that something does not 15 16 mention a physical risk does not necessarily mean that it is 17 a bad consent form if, in fact, it is for a project where there 18 are no physical risks, and so on for all of the bits of data. 19 In a similar study that I was involved in where we 20 did look at what was on consent forms, we found if we looked 21 at it in this way and said there is no mention of physical 22 risks, we might then look at the description of the project and 23 find that there were no physical risks. But on the other hand 24 we did find in a small percentage of cases there were some 25 things described in the consent form that didn't have to be

106 because they didn't exist. So there can be errors both ways. 2 I assume it is not possible to learn by the end of tomorrow 3 what the correlations are between what data were missing and whether or not they really should have been in there. 5 DR. TANNENBAUM: In other words, the correlation 6 between the risk of the project and the statement of risk in 7 the consent form. The information that we have about risk in 8 the project will come to us and is in our data tape with the 9 source being the principal investigator himself. He estimates 10 the risk. That is how we would know, on the basis of his re-11 port. We could do a correlation between the risk in the pro-12 ject and the risk as indicated in the --13

DR. LEVINE: It is possible, then, to correlate on a protocol-by-protocol basis?

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DR. TANNENBAUM: Yes.

DR. LEVINE: When it says that 88 percent of protocol mentioned had no mention of psychological risks, this could be terrible if 88 percent of the protocols really did present psychologic risks to the subjects.

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DR. TANNENBAUM: Yes.

DR. LEVINE: On the other hand, if 88 percent of the had no psychological risk, this is exactly the way it ought to be. I would like to make one other comment, and that is what of the meaning might be of the correlation between holding a job and not being a subject. We did learn during the visit to

Jackson that just as in the real world, the people who were 1 2 employed couldn't take the best jobs as research subjects be-3 cause they would lose their jobs because they would have to 4 take too much time off from the work. 5 DR. RYAN: Bob, they found the reverse. They found 6 the research subjects worked. 7 DR. GRAY: One figure related to that that Dr. Tan-8 nenbaum didn't quote, in my recollection, is that only 6 per-9 cent of the research subjects did not have a prison job, and 10 94 percent did have prison jobs. 11 DR. TANNENBAUM: That is correct. 12 DR. RYAN: Dr. Jonsen. 13 DR. LOWE: I think there is an answer, though, imme-14 diately in here, to Dr. Levine's question. If you compare 14 with 15 6, you get a very rough and ready estimate of what kinds of 16 risks existed and whether they should have appeared on the 17 form. I think it is here. 18 DR. RYAN: It is just not correlated on a project-19 by-project basis. 20 DR. LOWE: But you can make a very quick estimate. 21 DR. RYAN: Dr. Jonsen, please. 22 DR. JONSEN: Thank you, Dr. Tannenbaum, for this 23 study. It is very helpful. You began when you described the 24 subject, non-subject differentials to state a very general 25 profile of the kind of person who was a volunteer. Is it possible

to develop a more complete profile? I don't know whether you are scientifically, in terms of your science, like to do this kind of profile thing, whether it is legitimate or anything of that sort, but we have been plagued up till now with a profile of the typical volunteer that has been a generalization. I could practically describe him to you now. My impression from your statistics is that that is almost uniformly incorrect. I just wonder whether it is possible to draw a profile out of your statistics.

10 DR. TANNENBAUM: Yes, I think that it is, if you mean 11 by profile that we describe the characteristics, the demograph 12 characteristics of subjects, their average level of education 13 or the distribution with regard to that fact. You see that 14 kind of information in the appendix. Appendix A shows the 15 distribution with regard to that. However, if you want a con-16 trast in that profile between those who are subjects and those 17 who are not subjects, then I think that the information we can 18 give you would be more limited insofar as we have a special 19 kind and limited sample of non-subject prisoners.

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DR. RYAN: Dr. Cooke.

DR. COOKE: It was stated earlier this morning that prisoners may not be free to express their real beliefs, and I want to ask the question as to whether or not you could be getting, in a sense, the prison line, the party line in the prison in terms of the answering of all your questions in your

interviews, and whether or not there is any opportunity to 2 ask the same sorts of things of individuals who were in the 3 prison but are no longer in the prisons. That is question No. 4 1. Then, if you could answer that I have a second question 5 which is more a kind of general opinion that I hope you could 6 offer us. But could you respond to that one? 7 DR. TANNENBAUM: Yes, I certainly can. I hope you 8 don't mind my saying I think that is an intriguing idea, a 9 very interesting line to follow. This study doesn't make a 10 provision for such an analysis, but it can be done. Perhaps 11 it should be done. Under the terms of our present contract I 12 don't think we can do it. I know we can't do it. 13 DR. COOKE: It would seem to me, though, that that, 14 Mr. Chairman, is an issue that I would hope the Commission 15 would look at, later or now, as to whether or not there might 16 be some benefits from extending Dr. Tannenbaum's study to a 17 sample of individuals who are no longer in the prison. 18 DR. LOUISELL: How feasible would that be to do that 19 kind of supplemental study? 20

DR. TANNENBAUM: I think it would be difficult, just as many aspects of this project that we have taken on are very difficult. If we sat down together to talk about the technicalities of that, I think we might be able to work them through. I see it as potentially feasible. I think it could be done, although it would be a very difficult project to do, a matter

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of tracing some people and getting to them and getting their 2 responses to these questions.

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3 DR. COOKE: The second one -- and if you would prefet not to respond it would be perfectly appropriate. As you know, we have been wrestling with the issue of accreditation 6 as a way of giving greater protection. I have been espousing 7 out-of-prison research as a way of providing greater public 8 view and so forth, and you probably have done more right now 9 than most individuals to look at the situation. Can you give 10 us some general ideas from your own personal perspective now 11 that you have carried this out, as to what you would do in the 12 way of improving the situation, or nothing, for that matter? 13 DR. TANNENBAUM: Well, I am torn because of this quest 14 tion. I am not sure it is appropriate for me to do this. We 15 have made an effort here to present the facts and the opinions 16 of respondents whom we are interviewing, and to do so with as 17 little embellishment as possible. I am concentrating on that. 18 I want to get the facts before you as best we are able to do 19 that. We are therefore exercising a certain discipline, self-20 discipline with regard to making the kinds of interpretations 21 or explanations that you are asking us to do. We have to 22 shift gears, and I am not sure that would be constructive in 23 terms of what we are trying to achieve.

DR. RYAN: Dr. Jonsen wanted a quick -- on this point only.

DR. JONSEN: Just on this point. Instead of answer-2 ing Dr. Cooke's question directly, could you answer in this way? From your experience in gathering this data, could you 3 say whether or not you think an accreditation system which would be faced with data-gathering problems in prisons would 5 work? Have you found it extraordinarily difficult? 6 7 DR. TANNENBAUM: Have we found it difficult to gain entree and to acquire this data and so on? 8 9 DR. JONSEN: Yes. 10 DR. TANNENBAUM: I would say we found it remarkably easy, given the time limitations that we faced, and given the 11 minimum -- I would say the absence, from our point of view, of 12 effort to coerce. We went in there and explained that this 13 was voluntary. It is conceivable that some prison officials 14 felt that it was mandatory on their part, but at any rate, we 15 explained that this was voluntary from our standpoint and we 16 17 hoped they felt it was voluntary. Under these circumstances, 18 nonetheless we were able to get in , we were able to interview 19 prisoners, we were able to interview principal investigators, we spoke to some prison officials, and we didn't have the kind 20 21 of authority that I think you might have if you worked under 22 some kind of accreditation rule. 23 DR. RYAN: It is a very interesting experience. Ms. 24 King next, please.

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DR. KING: For fear -- since you offer us the only

facts that I have seen for a long time -- that the facts will 1 be overworked and be used to explain things that perhaps you 2 didn't intend them to mean, I want to go back to the demongra-3 phic statistics. As I understand it, you distinguish between 4 subjects and non-subjects, but in the non-subject pool you 5 attempted to draw no correlation between those people who ó worked in the prison population and their educational background 7 how often they worked, how many hours they worked, et cetera, 8 with non-subjects who neither worked nor participated in re-9 search. What I am trying to get at is the following. It would 10 not surprise me that within any prison that the highest-paying 11 job is the progression level to which all prisoners, unless 12 they had some reasons for being suspicious of certain types of 13 occupations, would gravitate to. So I wouldn't have been 14 shocked if the non-working, non-subject population may not 15 have been the lowest in education, the most suspicious, et 16 cetera, and that what we are really seeing in the prison sys-17 tem is what we see, perhaps, in the general society, and that 18 is that those who are most equipped to survive or to make it 19 through are those most likely to end up with the highest paying 20 jobs. I want to make sure that I understand how you drew your 21 non-subject population so that we don't extrapolate from your 22 data theories that it is the least coerced who participate, be 23 § 24 cause it all depends on how you are talking about coercion. DR. TANNENBAUM: Yes. Well, first let me repeat that ຊື່ 25

1 the non-subjects come from only two of the four prisons. 2 Secondly, they are a small number of persons, and therefore a 3 certain error is associated with the statistics that we cite 4 for that group. We selected them, however, on the basis of 5 probability methods, which means that we have, given the limi-6 tations I have just stated, a representative sample of prison -7 ers, with the exception of, let us say, those on detention or 8 those who we were not able to get to for reasons of special 9 security purposes. But to the best of our knowledge we have 10 close to a representative sample of prisoners. 11 DR. KING: As I understand it your sample was limited 12 and you decided to add it on at the end. You have not, however 13 done a breakdown of the non-subject population in a way that 14 would be useful to me if I were to look at a prison and look 15 at the three populations therein; those who participated in 16 research, those who worked, and those who did not work at all 17 and did not participate. 18 DR. TANNENBAUM: Yes, that would be lovely to do if + 19 unfortunately we don't have the number of cases that are re-20 quired for an analysis of that kind. It would take more data 21 so that when we broke them down into these subclassifications 22 we had substantial numbers in each of the classes. 23 DR. RYAN: Now, to go on, Dr. Louisell, please. 24 DR. LOUISELL: This is along the line of the quesâ 25 tions, I think, of Dr. Cooke and Dr. Jonsen, but perhaps a

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little bit different. As a result of all of your very precise 2 careful analysis here, have you come to any conclusion of a 2 3 personal or philosophic nature that you would care to express to us as to how relevant the prisoners' attitudes should be 5 in our overall conclusion? 6 DR. TANNENBAUM: I don't know whether I would say ó 7 how relevant, but I certainly agree it is relevant. I think 8 that this is what the prisoners are communicating, and they 8 9 understand that this information is being presented to you. 9 10 This is the message that they are sending to you through us. 10 I would say it is relevant. 11 11 12 DR. RYAN: Stephen Toulmin, please. 12 13 DR. TOULMIN: Pass. 13 14 DR. RYAN: Dr. Stellar. 14 15 DR. STELLAR: The question I want to ask may help 15 16 shed light on this issue that Pat King raised. I realize that 16 17 the number of non-subjects were very small and collected late 17 18 in the game, but wouldn't it be possible now, and I come to 18 19 this looking at the appendix, to get comparable data that are 19 20 appendix and related to the question that Ms. King had, from 20 21 the prisoners as a whole, the total population? For example, 21 22 you indicate that twelfth grade education is the most frequent 22 23 education of your subjects. It would mean one thing if the 23 24 most frequent education of the prison as a whole were third 24 25 grade, for example, and another thing if the most frequent

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education of prisoners as a whole were twelfth grade. So it goes for all the rest of the items in the appendix. I think in some respects if we can collect data on the prison population as a whole from which these subjects were drawn, we might be in a better position to use the information for profile-type purposes and also to answer the kind of question that Pat King has raised. I hope we can get that at some point, even in the next couple of days.

DR. RYAN: Excuse me. I imagine that some of that data is kept by the prisons themselves. DR. STELLAR: It should be. It would be important to have it for these five prisons. DR. RYAN: I have received something from Maryland prisons which I will enter into the record and have distributed to you that gives you some information on the characteristics of participants in research, and you will have that this afternoon, I hope. Mr. Calhoun, please. MR. CALHOUN: I was wondering about background information. Perhaps the question has been answered already. In terms of the investigators, were there differences in terms of whether the investigators were from drug companies, from university medical schools and that sort of thing, and if there were, were you able to find any variations in terms of some of the questions you raised about the nature of the consent form a 25 used by these various investigators in terms of perceptible

differences between these various types of researchers? 1 DR. TANNENBAUM: We didn't do an analysis of that 2 2 kind. It could be, but -- it could be done, but the number of 3 3 cases are relatively small. We are dealing with 41 cases. 4 4 DR. RYAN: Now, we are heading down toward lunch, so 5 5 please be brief. Brad Gray? 6 ó DR. GRAY: I just wanted to mention, in addition, you 7 7 indicated those data would be presented this afternoon from 8 - 8 Maryland. I think they are relevant at this point, and just 9 9 with regard to one thing. There are some comparisons there 10 10 of differences between the subject population over a 17-year 11 11 period and a one in a hundred sample of the prison population, 12 12 which is, I believe, consistent with the general line of con-13 13 clusions that are coming out of the study done by the Michigan 14 14 people. That is, the differences where they exist in education 15 15 are that the better educated subjects, the better educated men 16 16 tend to be subjects rather than non-subjects, from the Jessup 17 17 data. There are some other data there, too, but that is, I 18 18 think, relevant at this point. 19 19 The other thing that I would mention is that I think 20 20 that since there is an awful lot of material that has come to 21 21 you in the last month, there are a couple of things along the 22 22 lines of the information that is presented here that perhaps 23 23 should be drawn to your attention particularly. One is the p 24 24 by Jack Susman, which I think offers a larger, perhaps more 804 25 25

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theoretical context drawn from the overall sociological literature on prisons for understanding why the findings that we have here are what they are. There is little interpretation here, and I think it will perhaps provide a larger context. The other thing that I would like to mention, and John should do this himself, is the paper by John Irwin which also addresses directly the question that Dr. Louisell was mentioning. That is, to what extent should the views of prisoners be relevant to the Commission's deliberations. DR. RYAN: The Commission members have received all that information ahead of time, including John's paper, and I quess you have all received the material from Maryland in the mail, so you should be aware of it. Those who haven't, we can get it to you. John, the final word now, and then I want to break for lunch. DR. IRWIN: I want to add something in terms of the last statement. It seems to me that there is a strong indication that a consensus was reached by the subjects in these programs. You remarked that you were startled at first at the consistency of their answers, and I thought that when we visited Jackson that we watched a movement from the morning to the afternoon to a consensus. I thought that we were getting many more criticisms of the program in the morning when we were talking to persons. By afternoon, it was apparent to me that some kind of a group consensus about the program had been

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	1	reached and a lot of the criticisms had been stifled. I don't		7	That gives you approximately and he
	2	want to imply by this that there was any type of coercion and		2	
	3	so on, but I think that there was kind of some way it was com-		3	
	4	municated between the subjects that this was, in fact, a pro-	and a second	4	research.
	5	gram that they wanted to support and to present in front of		5	
ı	6	the Commission as something very, very favorable, and they were		ć	and i c clock pim. the same day.)
	7	very sensitive to the fear that because of the Commission's		. 7	
	8	action, it being stopped. So I am suspicious that some of		8	
	9	that did not also come through in the answers to these ques-	8 	0 9	
	10	tions.		-	
	11	DR. TANNENBAUM: Should I respond to that very quick-	1 1 1 1	10	
	12	ly? There is no trend that I can discern that indicates peo-		11	
	13	ple who are interviewed later in the day are more or less		12	
	14	favorable than those who are interviewed earlier in the day,	1 1 1	13	
	15	and the consensus that I referred to I didn't mean to imply		14	
	16	that there was an agreement, implicit or explicit, among per-		15	
	17	sons in achieving that. But that consensus exists across pri-		16	
	18	sons as well as within prisons. One prison is like another in		17	
	19	this respect. I hate to say that if you have seen one you have		18	
	20	seen them all. I hope I am not quoted in that way, as having		19	
	21	said that, but at any rate, they are consistent in this one		20	
ÂUC				21	
Comp	23	respect.		22	
Bowers Reporting Company	20 21	DR. RYAN: What I would like to do now is break for		23	
iwers Re	24	lunch and reconvene at a time when people will be here, which	ers Berry	24	
, B	25	I suggest should be 2 o'clock. Is that adequate for people?	BOW	25	

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hour and a half. Please

clock p.m. a recess was taken

AFTERNOON SESSION

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2:17 P.M.

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3 DR. RYAN: I wonder if we can reconvene for the 2 afternoon session, and before we begin our deliberations on 3 prison research I want to ask if there are any more comments 4 or questions anyone wanted to direct to Dr. Tannenbaum. He 5 is with us, 1 think will be here for the next day. I think 6 I might add for the record I perceive that Commission members 7 appreciate very much the information that he has generated 8 thus far, and I think it will be very helpful to us in these 9 deliberations on prison research. We hope to see much more 10 of it. 11 DR. COOKE: Mr. Chairman, is this the time to 12 bring up the question of pursuit of more information about 13 the prisoners who are no longer incarcerated? 14 DR. RYAN: It might be an appropriate time. The 15 only thing, Bob, is that you have two days, if we are going 16 to get into the question of prisoner research and make some 17 decisions. If there is information you feel is so necessary 18 that you cannot make these decisions, I think we ought to try 19 and get that information, but I would be disappointed if we 20 could not go on with our deliberations over the next day and 21 one-half and reach some direction for the Commission on how 22 we are going to come down on prison research. 23 DR. COOKE: I would hazard a guess that it will

24 DR. COOKE: I would hazard a guess that it will 25 come out confirming in-house collection of information. On

the other hand there are a number of critics. There may well be a number of critics of what we might come up with, and to respond to some of those criticisms more information would 3 be useful. Now, it might also be useful, it seems to me, 4 for the Secretary, if he is going to act on our recommendations 5 that there is additional information so that I would think 6 there might be an advantage, even though it won't influence 7 our own decisions in the next couple of days. 8 9 DR. RYAN: Good, please proceed. What are your recommendations? 10

DR. COOKE: Oh, then I would like to recommend 11 the development of a contract be pursued with the same group 12 to look at a small but hopefully representative sample of 13 prisoners who were used in research and possibly non-prisoners 14 I think that is probably less critical. I mean non-research 15 subject prisoners who have been released from prison and to 16 compare the results on the instruments used, compare the 17 in-prison group with the out-of-prison group. So, I would 18 like to put that in the form of a motion to make it possible 19 for discussion. 20

21 DR. RYAN: It is my understanding that you want to 22 have interviews of prisoners after they are released who have 23 either been research subjects or not research subjects and 24 to compare that to the kind of information which is obtained 25 while they are in prison.

	1	DR. SELDIN: Could I add another point just to	1	MR. YESLEY: What Er. Cooke
	2	lay it on the table? Pat King mentioned something this mornin	2	DR. RYAN: Excuse me. That
	3	which I think is fairly important to strengthen some of the	3	trying to do. I appreciate what Don
	.4	data we have. It has to do with an examination of the non-	4	in relationship to Pat's request, but
	5	research subject group in parallel fashion with the research	5	asked for is entirely different. It
	6	subject group so far as various characteristics go, their	6	handled by the same contractor and so
	7	education, just paralleling the thing. I think it would be	7	So, I think if we could keep the issu
	8	of enormous value if the five prisons which were explored	8	to respond to was the question of whe
	9	for their characteristics of the research subject be also	9	talk to subjects in prison, whether y
	10	explored overall, for the distribution of the same qualities	10	same answer as you would if they were
	11	in the prison population as a whole, just as she indicated,		MS. KING: A further point
	12	and I think that would be a very powerful	12	From that I may assume that the addit
	13	DR. RYAN: I don't want to confuse the issue	13	information made this morning the inf
	14	because	14	obtained or do I have to put that in
	15	MS. KING: I want to ask a point of information.	15	So, tell me how to proceed to telling
	16	I thought that what I was asking this morning might be	16	DR. RYAN: Let us just fini
	17	covered under the current contract. Am I correct?	17	then we will go next to the question
	18	It is not? That is what I wanted to know. So, this, too,	18	Charles Lowe?
	19	would involve just the demographic information for the	19	DR. LOWE: I just wanted to
	20	prisons and would involve an add on to the contract along with	20	remove the stipulation from his motic
	21	Bob's?	21	contractor?
Company	22	MR. YESLEY: If they went back and tried to get that	Aug 22	DR. COOKE: Sure.
ting Co	23	information with those they have already talked to that	ပိ စူ 23	DR. RYAN: Does everyone un
ts Report		conceivably is within the contract.	oday 24	wants now? It is to try to interview
BOWEIS	25	MS. KING: That is what I asked this morning.	²²¹⁰ 8 25	been released from prison.

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ke is referring to is -it is what I have been has just asked for it what Dr. Cocke has t might or mi ht not be so on. We don't know. sues clear what Bob wanted hether or not when you you are getting the re outside of prison. t of clarification. itional request for nformation then will be n the form of a motion? ng Bob how to proceed? nish with Bob first, and on that you have.

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to ask whether he would tion that it be the same

understand what Dr. Cooke iew people after they have

MS. KING: May I ask him to clarify his motion?
Do you mean to include by that, Bob, people who are now
outside of prison but who may be participating in biomedical
research as ex-prisoners or did you want a completely
separate class? I don't understand what you meant. You
want people outside prisons?
DR. COOKE: I think that it would be probably

8 or might be a biased sample. It might be a biased sample if 9 you went to individuals who are now out of prison, who were 10 prisoners and who are now in research as subjects similar 11 to the Arnold group. So, I would rather have them come from 12 the same prisons who are not in biomedical research and so 13 forth and see what their responses are.

14 DR. RYAN: Eliot Stellar?

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DR. STELLAR: Do you mean subjects who were ex-subjects.

DR. RYAN: Stephen Toumin?

DR. TOULMIN: I think it is clear what the question is to which Bob wants an answer. I, therefore, hope he can frame his motion in such a way that the contractor, whoever he is, is allowed to make suggestions about which classes of people it would be most appropriate to interview and what questions it would be most appropriate to ask them. I mean, it seems to me to be silly to spend our time here arguing about which exact group we want to define as being the recipients of these questions, because clearly there are a lot of questions that will enable us to get the grounds for making a comparison between the people we studied up to now and the answers we got to them and other people who would form useful objects of comparison in order to see what weight we should put on the answers we have to date. I think this is what is wanted.

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DR. RYAN: I think that the length of time that 8 such a thing might take, its feasibility will have to be 9 explored, clearly. This is not a ready group of available 10 subjects waiting somewhere, and so all we need is an 11 indication from the Commission that they are interested in 12 that kind of information, realizing that it may not come to 13 them for several months but that they want the information. 14 If we have that, then staff will prepare and check out the 15 feasibility and the other things. 16 Any other comments about just Dr. Cooke's request, 17 no embellishments, please, or we will get bogged down. 18 19 DR. COOKE: There is another important by-product it seems to me. One of the issues in regard to experimentation 20 on prisoners was the issue of the long-term consequences of 21 the procedures that were carried out, and one of the things 22 we would certainly learn about this is how maybe some 23 mechanisms or the difficulty of follow-up of prisoners who 24 25 were in such research, and that might have some significance

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1 in terms of future regulations in regard to the conduct of 2 the research, the follow-up mechanisms, et cetera. So, I 3 think there is an additional advantage to going ahead with 4 this. 5 DR. RYAN: Brad, did you have something? 6 DR. GRAY: Just a comment, that an awful lot is

known about the problem of following up ex-prisoners. There 7 are a lot of studies that are done that way. We don't have 8 to do a study to learn how hard it is to follow-up ex-prisoners 9 DR. RYAN: Okay. I am not sure that we are going 10 to do a study. What you are going to do is to tell us 11 whether we can do them, whether we can issue a contract and 12 get it done. That is what we want. Okay, do you think it 13 is very difficult? 14

DR. GRAY: If you would like some reactions, I think it is very difficult. I think that we will have to start with an RFP. We will have to go through OMB with a questionnaire and the whole thing. It will be months. You are right about that.

DR. RYAN: Do I have a second for Dr. Cooke's motion? (The motion was duly seconded.)

DR. RYAN: Okay, the first thing you will get
back is the staff work to react to. Other discussion?

If not, all those in favor?

(There was a chorus of ayes.)

DR. RYAN: Is there anyone opposed? 1 Now, the next question is with respect specifically 2 to Dr. Tannenbaum's study, and that is whether we can get 3 better demographic information on the total prison populations and on not only the research subjects but 5 individuals in prison who are not research subjects. 6 MS. KING: Ken, I assume, and I am just asking 7 a point of clarification, that whatever I said this morning 8 was sufficient to take care of it. If that is not so, I will 9 put it in the form of a motion so that you can tell me how 10 to proceed. 11

DR. STELLAR: Could I make one point? I asked 12 Dr. Tannenbaum and Brad about this during the lunch period, 13 and they seemed to think they could pursue this question. 14 Is that correct, Brad? 15 DR. GRAY: We can pursue it. There are two 16 problems. I am not sure whether we are talking about 17 restricting ourselves to what is in the prison records in 18 those prisons or whether we are talking about going back and 19 interviewing a random sample of prisoners in order to get 20 the ---21

MS. KING: Mine was purely the kind of information that was raised this morning that had to do with formal education level. It had to do with what kinds of jobs people held, how long they worked, who did not work, basic

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1.28 129 information. You started on the subjects and a little bit 1 relatively weak one. To get the information that is, say, on the 45 groups. I asked for a split-out of three groups 2 more definitive or more solid, we would either have to 2 with that kind of information, and I also asked for overall 3 interview a larger number in several additional prisons or 3 racial composition, broken down by prisons if that was not 4 we would have to get records from the prisons themselves. Δ going to get to be a confidentiality problem in terms of 5 That would represent additional work which we have not 5 racial composition. 6 planned and did not anticipate as part of our arrangement 6 I thought it was a fairly simple request. I did 7 with you. 7 not think I had to make an additional motion, but I will if 8 DR. COOKE: Dr. Tannenbaum, if you wrote a letter 8 I have to. I just wanted to know whether it would be taken 9 to the prison and said, "Would you please tell us about 9 care of by that request this morning. 10 your overall population in regard to the following, the 10 DR. GRAY: My impression is that it is not a simple 11 amount of education level, the race distribution, and so 11 one to me, and perhaps Dr. Tannenbaum should comment on that. 12 forth?" I would hazard a guess that we could get that 12 DR. RYAN: Dr. Tannenbaum, could you respond 13 information very easily. 13 please? 14 DR. TANNENBAUM: Good. I think if the data are 14 DR. TANNENBAUM: I was sitting back here and did 15 available it seems to me likely that we would get them, in 15 not catch all of the conversation, but I will try to address 16 other words that the prison officials would make them 16 myself to the question that I think you are talking about 17 available to us, especially if we could ask them in the 17 and that is whether it is feasible to obtain data that 18 context of the request from you, that this is important in 18 describes the demographic characteristics of non-subjects 19 terms of your deliberations, and I feel reasonably confident 19 that we can compare those non-subjects with the present 20 that they would provide it, if it is available. 20 sample of subjects. 21 21 My understanding of the way records are kept, not We have, as you know, data from 45 such non-subjects 22 in prisons particularly, but generally in organizations, that 22 It is a limited set of data, and we have demographic, some 23 23 sometimes they are not in an order, in a condition that demographic information about them. We can, therefore, 24 Ser lends themselves to requests such as this, but we can try 24 provide information and give some comparison, but it is a 25 ⁸ 25 that, and I have no objection to doing that.

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DR. RYAN: Okay. Then I would ask, does this 2 meet your needs?

3 MS. KING: I quess I had better make it in the 4 form of a motion. I move that Dr. Tannenbaum -- I had 5 better change that. I had better say that Dr. Tannenbaum, in conjunction with our staff, as far as feasible, within 6 the contract, seek to obtain for us additional demographic 7 8 information with respect to the five prisons studied. I am 9 not asking that they go outside the five prisons, with 10 respect to the five prisons studied. I have in mind racial 11 composition data which should be fairly easy to obtain in a form broken down consistent with the confidentiality 12 provisions. 13

14 I, also, have in mind information of the type already developed in the current report about the 15 characteristics of the subjects with respect to things like 16 formal education, jobs, background, et cetera, with respect 17 to the prison population to the extent that it is feasible 18 to obtain such information, and if it is not feasible, I 19 20 would like to have a report back to the Commission at the next monthly meeting of the Commission telling us what it 21 was possible to do and what was not possible to have done. 22 It is a complicated motion. 23

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DR. STELLAR: I second that and add one thing to it, 24 S. that is that we make sure, insofar as possible that we get 25

information of the sort that Pat asked for on the items included in the appendices. If we are to interpret those 2 I think it would be very helpful. 3 DR. RYAN: Thank you. Is there further discussion of this now? Dr. Jonsen? 5 DR.SELDIN. I just have one suggestion. Why 6 can't we have a contingency motion that in the event it 7 cannot be obtained for some reason under the present 8 contract that the staff look at other ways of doing it? 9 DR. RYAN: I think one of the questions the 10 Commission is going to have to decide today and tomorrow 11 is whether or not you are going to make a decision on the 12 13 prison issue and how much additional information you want. I think that we cannot keep generating information we are 14 not going to use. 15

DR. SELDIN: I think this sort of information would 16 be valuable even if we don't use it specifically here, because 17 it is parallel and in conjunction with the information we 18 have on subjects. 19

20 DR. RYAN: That is what I want you to say. 21 DR. SELDIN: I am saying it. 22 DR. JONSEN: I suggest that there might be a problem 23 with defining the class of non-subjects, that is non-subject 24 and subject are not parallels. A class of subjects is 25 identified because they have made a decision to participate.

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1	A class of non-subjects is people who have either refused		
2	or who have not yet made the decision, and therefore to	1	not feasible some alternate means o
3	investigate the class of non-subjects might leave you looking	2	told.
4	at a population many of whom will later on at some other	3	Other discussion?
5	time become subjects or who may have never considered the	4	All those in favor of Pat
6	matter, and so we do have a peculiar for Bob's sake, I	5	(There was a chorus of ay
7	will use the word "dismorphic," two dismorphic classes.	6	DR. RYAN: Anybody oppose
- 8	DR. COOKE: No more than anyone else.	7	Thank you.
9	DR. JONSEN: No, this is very much something else	8	Now, I don't know how you
10	because I would be very leery about drawing conclusions	9	rest of the afternoon, but I think
11	about the class of non-subjects in the same way in which I	10	MS. KING: I have a sugge
12	would draw conclusions from the class of subjects. That	11	for the Commission, if they would h
13	does not apply, however, to any descriptions which one would	12	start in discussion I would like to
14	want of general prison population.	. 13	to the Commission what it was that
15	DR. COOKE: I think that the numbers of subjects	14	you or Charles or Michael had in mi
	are so small in relationship to the total that it really	15	to do because I think it would be h
16	washes out as far as, you know, it seems to me we ought to	16	I assume that you all had
17	take all the prisoners, use that demographic data and	17	to accomplish, and I think it would
18	then draw our conclusions from a comparison of subjects used	18	start that, and you could tell us w
19	in general prison population without worrying about the	19	of this meeting, and then perhaps w
20	non-subjects.	20	react to that before we started. I
21	DR. RYAN: We will get the report back or the	21	DR. RYAN: I think what w
22		hund 22	the deliberations aspect of a forma
23	feasibility back within a month, if you vote on it. Is there	⁵⁰ ອະ	this Commission to the Secretary ar
24	further discussion on this?	tioday 24	with respect to prison research. I
25	And I presume Dr. Seldin's suggestion that if t is	siamog 25	simple as saying, "The Commission r

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of getting it will be

at's motion say aye? ayes.)

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you want to structure the nk we must -- yes? ggestion for the chair or a be so kind. Before we to have somebody explain at you had in mind about mind about what we were

helpful to me. ad a goal that you wanted ld be helpful if we could what you want to come out we could attempt to I would appreciate it. we are starting now is mal recommendation from and to other federal adjencies It might be something as recommends that no prison researach be conducted" and append all of the information
 and embellish that with a staff report. It might be that
 we countenance research, but we must start now in our
 deliberations to develop the Commission position and report.

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5 MS. KING: Was it contemplated that we finish? 6 I am talking about in terms of what your objectives were. 7 I know what you want. You want us to reach a product. My 8 question really goes to the time frame which you have planned 9 for us to hopefully reach whatever product we are going to 10 turn out and a further question so that you can respond to 11 me all at one time.

12 If the original contemplation was this weekend, 13 that we would finish either by Saturday or by Sunday, then 14 what was planned in terms of future staff rewrite, when it 15 would come back to the Commission? Tell us that so that 16 we will know how to structure our own time and thinking.

DR. RYAN: I think that really what we hoped to have evolve from this meeting is our general approach to the problem. I don't expect that we are going to have a final report this weekend. I think that the staff has to hear the Commission discussion and then incorporate that and synthesize that into our final report.

MS. KING: When was the final report, Michael?
When did you contemplate it? We did everything you wanted us
to do this weekend. When did you contemplate that you would

1 have a report block to us so that we could take official 2 action? I assume this report is to issue before the 3 Commission's final report is to issue, and I am trying to get 4 a more accurate picture.

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5 MR. YESLEY: If we have the bulk of the Commission's deliberations which can be summarized as 6 deliberations or deliberations and conclusions as a portion 7 of the final report and in addition we have votes taken on 8 specific recommendations, then a draft of the report can be 9 circulated prior to the next meeting, and you can take it up 10 one month from now with respect to final language or any 11 changes that you want to make, but we need enough material 12 from which to compose the entire deliberations, plus votes 13 on specific recommendations. 14

DR. RYAN: I would also call to your attention that you have under Tab 1 the staff report on bibmedical behavioral research involving prisoners which is a summary. It is a summary composed of some 81 pages. I hope all of you have read it.

In the back of it are questions to be resolved by the Commission as the staff saw it, and some recapitulations and general comments. I, also, want to remind you about the committee that the federal penitentiary system used in reaching their decision about prison research. Their report is in here, and that is a synopsis.

In point of fact, they all come down, everything we have heard about revolves around two fundamental issues. One is 2 that prisons are a bad environment, either for giving 3 informed consent or getting anything done for people, and for that reason, things like research where there are 5 ethical considerations, you can embellish that in any way 6 you want, but that is one pole of the issue. Are prisons 7 so coercive that nothing can go on there? The other is that 8 prisoners have rights. That is the other extreme of this, 9 and they have constitutional rights, and we should not 10 abridge them. Therefore, research should be allowed, but in 11 any case someone would want safequards. Somewhere between 12 those two poles we are going to have to come up with 13 specific recommendations. 14

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DR. LEBACOZ: Yes, I was in fact going to suggest 16 that we might structure our discussion by addressing the 17 specific questions that are listed on page 76 of the staff 18 report, but I, also, want to ask that we have sometime this 19 weekend when we can address the remainder of the staff report, 20 so that if we have questions or comments about some of the 21 remainder of that we can also get those concerns out on the 22 board for the staff to be reworking, and I do have several 23 such comments. 24

Karen wanted to be heard.

So, I would like us to block out some time during

the course of the weekend where we do that. We might not 1 want to do that until after we have done our own deliberations. 2 3 DR. RYAN: Yes, Pat? MS. KING: I would like to move, and I would make this in the form of a motion, that the Commission structure 5 its discussion in two separate categories, that we first 6 address the issue of prison research or research in prisons 7 8 with respect to biomedical research and reach some conclusions and vote recommendations for biomedical research 9 and then take up the issue of behavioral research in prisons 10 and make it -- if I hear a second I will explain why I 11 suggested that. I am afraid that if we don't do it that way 12 that the complications that arise in trying to discuss the 13 14 two issues at the same time will weaken and slow down the discussion rather than speeding it up, and if they need to be 15 put back together after we discuss them separately it seems 16 to me it is easier to do it that way than to try to discuss 17 18 them together.

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19 DR. LEBACQZ: I will second that motion. 20 DR. RYAN: Everyone sees it the same way. 21 I mean we have got to discuss them separately because there may be issues that have to be resolved. MS. KING: Good. DR. RYAN: Now, are there any other comments or suggestions that people have to make with respect to this?

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1	DR. JONSEN: Mr. Chairman?		attempt to define what those circumst
2	DR. RYAN: Yes.	2	this by its very nature would say tha
3	DR. JONSEN: Where is the document from the	3	prisoners to participate providing ci
4	federal prisons?	4	and such.
5		5	DR. RYAN: That is your und
6		6	I want to hear it from the rest of th
7	the letter from Carlson to Caspermyer. It is dated March 10,	7	DR. COOKE: I would like to
8	Federal Bureau of Prisons.	8	definitely gets us away from a catego
9	DR. COOKE: ' Does it say anything that we don't		MISS KING: I want to say t
10	already know?	9	
1)	DD DVAN. In point of fact, I don't mean to be	10	
.12	the sector oversimplify it, but those are the	11	and that is that although prisoners m
-13	Dricopors have rights and prisons are coercive.	12	
1	Titles were going to stop prison research or you are	13	
1.	in the superty conditions under which they are acceptable	14	
		15	
] (NR COOKE: Mr. Chairman, I would like to open it	16	
1	I think we have already said this, and that is why I	17	I think, very accurate in picking up
1	I think the	18	the consensus.
1	maybe it was just a straw vote on this	19	DR. RYAN: They always are.
2	proposition that no person or class of persons should	20	Okay, I think that that is
.2	categorically be excluded from participation in biomedical	21	to come to grips with, and if we star
upduo	2 categorically be excluded 11th 1 3 research. That was, I thought, what we had agreed on at one	100 22	kinds of questions that Karen suggest
Reporting Company	<pre>3 research. That was, I thought, and 4 time, and that it was under certain sorts of circumstances</pre>	Button 23	the requirements for informed consent
ëgwers Rep	time, and that it was under our carry out, and we would that it would be permissible to carry out, and we would	day 24	down the path which we think under ce
-Bior	that it would be permissible to their	^à 25	research may be carried out. I would
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stances were, but that hat it is possible for circumstances are such

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o vote that so that it gorical ban.

that the staff statement of what we arrived at, may not be excluded ciple, there may be we to be excluded. That we have gotten. Now, s suggesting, but I think ed at this time for being, o what turned out to be

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s the issue that we have art getting into the sted we start with, like ht, we are leading ourselves certain circumstances ld not want to get into a

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	1	long, elaborate discussion and then find out that most of		all possible worlds, on principle ye
	2	the Commissioners felt that research should categorically not	2	Okay.
	3	be carried out in prisons.	3	No discussion of that?
	4	So, how do we get started.	4	All those in favor of tha
	5	DR. COOKE: There is a motion.	5	MS. KING: I think we had
	6	DR. JONSEN: What is the motion?	6	discussion.
	7	DR. COOKE: The motion is that the Commission	7	DR. LEBACQZ: I have a po
	8	support the proposition that no person or class of persons,	8	that. I am troubled by the fact th
	9	including prisoners should be categorically excluded from	9	because my recollection of our disc
	10	participation in biomedical, if we want to separate it off,	10	Bob was one of those who was moving
	11	biomedical research.	11	excluding prisoners on principle fro
	12	DR. JONSEN: On principle.	12	Now, I, personally, do not object to
	13	DR. LEBACQZ: If you make that on principle, that	13	floor before us at this time, but I
	14	would make a difference.	14	come out saying that everyone who is
	15	MS. KING: It sure would. I don't think that is	15	raising objections has nothing to se
	16	what Bob wants to do.	16	Bob were here he might.
	17	DR. RYAN: Is there a second to that?	17	DR. RYAN: It is laudible
	18	(The motion was duly seconded.)	18	but everyone was asked to be here,
	19	DR. RYAN: What is the discussion on this?	19	DR. LEBACQZ: I understand
	20	DR. LEBACQZ: Do I understand that the phrase on	20	remind the Commissioners that some
	21	principle is included in here?	21	last discussion that I think would
Jupduk	22	DR. COOKE: It is a kind of a principle anyway,	k 22	side of that, and they might need to
ng Con	23	but it is okay to put "on principle."	ы б 23	about it.
Rowers Reporting Company	24	DR. LEBACQZ: There is a difference.	uitroda 24	DR. COOKE: I believe on
ROWERS	25	DR. RYAN: So, what you are saying, in the best of	sianneg 25	Bob Turtle and I were in agreement

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you might allow this..

hat then?

ad better have some

point for discussion about that Bob Turtle is not here, scussion last time is that ng in the direction of from participation in research. to the motion that is on the I would not want us to

is here because we are not say. I am aware that if

le for you to bring it up, , Karen.

and that. I just want to e points were raised at our d have spoken to the other to be reminded to think

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n the principal issue t that, for example, if

1	142 there was adequate public exposure if there was research	
2	conducted outside the prisons, et cetera, he, at least,	•
3	privately indicated to me that that would be acceptable.	1
4	So, I don't think he would oppose the on principle that they	3
5	not be categorically excluded, although at one time in his	4
6	argument it sounded like that.	5
7	DR. RYAN: Dr. Jonsen?	6
8	DR. JONSEN: I think we have got a funny proposal	7
9	here. Is anyone here willing to argue strongly against it?	8
10	And if so, can they tell us what they would mean by on	9
11	principle excluded? What I understand, when I hear someone	10
12	say on principle is that there is something about the class	11
13	of beings called prisoners that of their very nature	12
14	disqualifies them. For example, and I mean this is simply	13
15	an example, one person might say of someone who has been	14
16	condemned to prison they are unworthy by that very fact of	15
17	ever volunteering to do anything good for society and therefor	16
18	whoever belongs to the class of condemned criminals is on	17
19	principle, on that principle excluded.	18
20	Now, it seems to me if we are going to make any	19
21	sense out of this proposal that is on the floor that we at	20

implicitly making. It is quite clear to me that some of the practical reasons for which they might have to be excluded which are referred to at the end of Item B4 on page 78, that some of these practical reasons might include, might raise methods of principle. So, it is not clear that the 5 distinction between on principle and in practice is itself 6 a clear distinction. In fact, I think the reason why the motion is not attracting any discussion is because there 8 Some interpretation /which anybody could accept/ It is / 9 seems, therefore, to me to be a cloudy motion, and I am not 0 sure that a vote on it would throw any light on anything. DR. COOKE: 1 think the advantage in defense of 2 my motion is that it puts down firmly the fact that a ban as such would not be acceptable to the Commission, just because they are prisoners as such, too powerless, et cetera, and for that reason out. DR. RYAN: Pat, do you want to --MS. KING: I think that what is troubling me because I think I understand what Al is trying to get to, and I think I could agree with my own interpretation of what is meant. It is because the motion is stated in the negative. We talk about ethical principles, and the way this should be stated is something that we agreed to last time, that no human being or category of human beings should be categorically excluded from research, not to focus on prisoners or anything

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DR. TOULMIN: I don't wish to argue this case. I just want to underline the point that Al seems to me to be

least ought to hear somebody argue that case. Is there

anybody willing to argue it?

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	١	else. We accept it as an ethical principle that our humanness		
	2	or the fact that we are human beings means that we have a		(Plug to recorder accidenta
	3	right, and this is at a theoretical level or an entitlement	2	DR. RYAN: How many hours of
	4	to participate as any others participate. Now, what limits	3	missed?
	5	we place on that is something else again, and I think my	4	REPORTER: Maybe three or f
	6	trouble with the motion is not that I disagree with it. It	5	DR. RYAN: Okay. Is it wor
	7	is too narrow for me. I would prefer to go back to work from	6	REPORTER: Yes.
	8	our basic ethical principle and to start right there which	7	DR. RYAN: Okay, Dr. Jonsen
	9	I have no trouble with doing, and if that is all Bob is	8	DR. JONSEN: I am thinking,
	10	meaning what he started to say is not what I mean. I	9	composition is getting compoundedly c
	11	do mean that from the Belmont discussion that as a matter of	10	proposition excluded from research
	12	speaking of ethical principles, no category of human being	а - 11 а	say, "No one has the right to be excl
	13	should be categorically excluded, and that it at a	12	What does it mean to exclude from rese
	14	theoretical level.	13	I assume what we are getting
	15	DR. RYAN: Do you have that quote?		everyone who is capable of volunteering
	16	MS. KING: No, but you said that it would not	15	be allowed to volunteer or we might me
	17	support a ban.	16	a potential subject of a researcher's
	18	DR. RYAN: Please include all of us.	17	they volunteer.
	19	MS. KING: Bob is telling me that I am wrong in	18	In other words, it is not at
	20	saying something. I was trying to say that is not necessarily	19	it means to say that no one should be
	21	what I just stated, consistent with the statement that I would	20	DR. RYAN: I want Pat to rea
any	22	not support a ban on research in prisons. I cannot, in my	21	manifesto.
g Company	23	mind, anyway, see being consistent with supporting a ban	up 22	MS. KING: I am actually rea
Reporting	24	but not being in principle opposed or in principle excluding	e 23	paper, and I think that this will clar
bowers Reporting	25	anybody.	day 24	very desperately to say.
			ŝ 25	Page 16, under Tab 4. Partic
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sen and then Dr. Brady. ng, also that our r confused, because the -- what does it mean to coluded from research"? esearch?

ing at is something like ring for research should mear that anyone is 's actions whether or not

at all clear to me what be excluded on principle. cead from the Belmont

eading from Stephen's arify what I was trying

ticipation in biomedical

146 behavioral research as a research subject may, in different cases be either a benefit or a burden. Insofar as it is a 2 2 benefit, particular groups or individuals should not be 3 3 systematically excluded from opportunities to participate, 4 wrote and use that as a basis for --4 except where the nature of the problem under investigation 5 5 MS. KING: I did not write it. specifically requires it. I think he is getting there at 6 6 what I am talking about, and that is that the benefits and 7 7 burdens and that no one should be excluded systematically 8 8 from being able to participate --9 tion in biomedical behavioral research as a research DR. JONSEN: What that means is no one is to be 10 10 subject may in different cases be either a benefit or a excluded a prior right from being a beneficiary. 11 1.1 MS. KING: Right, yes. 12 12 individuals should not be systematically excluded from DR. RYAN: Go on. Finish the paragraph, please? 13 Na-13 opportunities to participate, and except where the nature of MS. KING: Conversely, insofar as participation 14 14. is a burden, particular groups or individuals should not be 15 15 and conversely if it is a burden no one -systematically selected to carry this burden. If anybody 16 16 wants to make that a motion, I would be willing to go with it. 17 17 That sums up what I was trying to say. 18 18 DR. RYAN: Sometime this weekend we are going to 19 19 have to review the ethical paper and the boundaries paper as 20 20 well for a first cut, but we are running into difficulty 21 21 I would like to lay out what those circumstances are. with the way Bob has phrased his question. 22 22 DR. RYAN: Karen? DR. COOKE: Could I try once more? No person or 23 23 class of persons should categorically be excluded from being 24 24 offered a choice or the opportunity to choose to participate. BON 25 ^a 25

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DR. RYAN: What is wrong with just endorsing what the ethics committee has already -- it is going to be the solid basis if it is accepted, and that is what Pat just

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DR. RYAN: I am sorry, what Pat just recited to us. Doesn't that make sense? A lot of thought went into it. A subcommittee of the Commission and staff did it. Participa-

burden. Insofar as it is a benefit, particular groups or

the problem under investigation specifically requires this,

DR. COOKE: I don't want to put it simply in terms of whether there is some benefit. That is exactly the point. I think that every individual ought to have the opportunity to choose to participate, whether it is to his benefit or not, providing the circumstances are such and such and such, and

DR. LEBACQZ: I have a comment specifically directed to that. Bob, I think that the ability to participate, to make a free choice can itself be considered a benefit. The

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	1	word benefit here is not intended to mean a benefit deriving		DR. SELDIN: No class of i
	2	from the research in terms of one's health care or whatever,	2	
	3	but one's freedom of choice is itself considered a benefit.	3	
	4	So what this is saying is that freedom of choice should not	3	see, what you are really saying is t
	5	be systematically certain groups should not be systematical		
	6	excluded from having freedom of choice.)	categorization of people should not
	7	DR. RYAN: We have a motion which is	0	considered on a priori grounds as rea from research. Each should be examin
	8	DR. LEBACQZ: Your concern is incorporated here.	/	it is not a vacuous statement to my m
	9	DR. RYAN: 'Excuse me. We have a motion on the	9	say in the case of prisons, for examp
	10	floor which is being discussed, but the discussion seems to	10	
	11	suggest that a lot of people have trouble with it, and that	11	some enlightened prison, we will say,
	12	it is not going to be helpful.	12	somewhere in the world and that by an
	13	Don Seldin, do you want to add	13	one could distinguish this. So, we w
	14	DR. SELDIN: I really have less trouble with Bob	14	or those in prisons. We will make th
	15	Cooke's motion than others have. I think, if I understand	15	scrutiny, similarly in the case of le
	16	him right, what he is saying is that one should not designate	16	
	17	a class of human beings as systematically excluded from	17	
	18	research on a priori grounds. That argues that such people	18	circumstances research on them might]
	19	as prisoners may or may not be	19	other circumstances not. In short, I
	20	DR. RYAN: Okay. Excuse me. Is that what you	20	important statement in the sense that
•	21	agree with, that simple statement? Repeat it again?	21	statement, in the sense that it specif
mpany	22	I mean if you go on we are going to lose the thread	În 22	right, so to speak to participate in r
Reporting Company	23	of it, and if everyone agrees to that, then we can vote it,	wo 23	be systematically examined and then examined and the exa
ris Repo	24	that no one should be systematically excluded on a priori	troday 24	grounds.
BOWERS	25	grounds from research. Is that what you said?	Sianog 25	DR. RYAN: Okay, Michael?

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individuals --

individuals. Well, you
that some broad
systematically be
reasons for being excluded
ned empirically, and
mind, because you might
mple, that prisons vary
on camp, let us say, to
y, that might exist
an empirical scrutiny

wouldn't exclude prisoners this an empirical let us say research on ussed or on individuals t under certain t be permissible, under I think it is a very at it is not a vacuous cifies that there is a a research which should excluded on empirical

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	- 1	MR. YESLEY: I just want to say that I think what		
	2	you want to make clear is that not excluding on a priori	1	Now, it is clear tha
	3	grounds implies under appropriate conditions you can do it.	2	sentenced to a term in prison
	4	I am not sure that you can make that jump. If you can do it,	3	individual from taking foreign
	5	then Bob's motion does what he wants it to do. The question	4	number of things. I mean the r
	6	is whether you can make that jump.	5	to a term in prison ipso facto
	7	DR. RYAN: Well that is, of course, the evolution	6	exclusions, and the substantive
	8	of our deliberations, I expect, and that is why I want to get	7	is whether exclusion from the c
	-	this over and get on to more substantive things about	8	research is or is not one of th
	9	prisoners, if we can. If this is the first step, let us	9	man is subjected simply in virt
	10	take it.	10	prison term.
	11	DR. TOULMIN: As a professional teacher of	11	Now, this is a substa
	12	philosophy I am highly suspicious of the use of philosophical	12	not an a priori ethical asserti
	13		13	which is before us. Is this wh
	14	jargon. I mean I am very distrustful of phrases like in	14	a stand on?
	15	principle, a priori and the rest. It seems to me we have	15	DR. COOKE: I think I
	16	two issues here.	16	
	17	On the one hand we have a very general issue which	17	in general, prisoners in partic
	18	is the issue on which we have already tried to do our best There	18	
	19	on page 16 in the paragraph that Pat read out. / seems to		DR. TOULMIN: I mean
	20	me on the other hand to be another quite distinct issue which	19	is not something like going on
	21	is a substantive issue which is being run together with it,	20	should be excluded from simply
Aupd	22	and which I would phrase as followsand I think it is clearly	21 >	sentenced to a term in prison.
ig Company	23	distinct from the general issue that the mere fact of being	Compaul Compaul	DR. RYAN: Okay, Pat?
Reporting	24	sentenced to a term in prison is not a ground for excluding	bulling 23	MS. KING: I am not a
BOWERS	25	an individual from the opportunity to participate in research	day 24	to think of that in one, two, t
			⁸ 25	that what Stephen said a few mi
			2	

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r that the mere fact of being ison is a ground for excluding an reign holidays or for doing a large the mere fact of being sentenced facto carries with it a lot of antive question we are facing here the opportunity to participate in of those exclusions to which a n virtue of being sentenced to a

substantive question in penology, ssertion. It is one of the questions his what Bob is wanting us to take

nink I could stand with Don's statement second, that is people articular.

mean participating in research ng on a foreign holiday which you mply in virtue of having been

not a philosopher, but I will try wo, three terms. It seems to me Tew minutes ago is critical not

only to this deliberation but to every other and that is 2 that we take each small step, step by step deliberately so we don't lose each other. It may seem silly to start with 3 this basic ethical principle, but we have got to start here Á and understand what it is that we are saying before we can 5 then get to the way Stephen phrased the next problem which 6 we may not be able to agree on right now, and I don't like 7 Don's phraseology a priori. First of all, this paragraph 8 I have been studying is a gem. It dealt with the specific Q problem. 10

I am very serious. If you look at this, except 11 for the nature of the problem under investigation specifically 12 requires this. Nowhere in the motions that I have heard on 13 the floor has that problem been addressed because we are 14 still up in the clouds we had not thought about it, but SO 15 it is has been thought about in this particular paragraph. 16 I don't understand what the a priori language does that this 17 paragraph does not, and I also cannot understand quite 18 frankly why we cannot just say on the prison report we 19 reaffirm the ethical principles. We will now vote on that, 20 and we will proceed to the next question. Are we willing to 21 ban research in prisons on the fact that a person has received 22 a jail sentence. 23

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DR. BRADY: If you leave off the first phrase of that 24 sentence you have met Bob's concern about it, too. 25

DR. COOKE: Yes, that benefit one --DR. BRADY: If you leave off the "insofar as it 2 is a benefit." That is not necessary. You would start with 3 particular groups or individuals should not be systematically 4 excluded from opportunity to participate. Why is the first 5 part necessary? 6 MS. KING: Because I, also, like the last sentence. I think that says something very important, too. 8 DR. RYAN: Excuse me, Pat. He did not exclude the last phrase which was except where the nature of the problem 10 of the investigation specifically requires --11 DR. BRADY: I was thinking about the next 12 sentence, too, that she wants in there. Conversely, insofar 13 as participation is a burden, particular groups or individuals 14 should not be systematically selected. That I think we can 15 get in there, too, without mentioning the risks and benefits 16 and burdens. You don't have to mention benefits or burdens 17 at all. Groups should not be systematically excluded nor 18 systematically required to carry --19 20 DR. COOKE: That might be a useful addition if we 21 are going to talk about concordance. 22 DR. RYAN: David Louisell, please? 23 DR. LOUISELL: I really think we are wasting time 24 on a sheer procedural matter and just delaying the inevitable a 25 hard grappling with the substance of this problem. I think

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in any event, Bob, what you say is a little premature, your proposition at this time. There are certain questions of 2 information that I want to ask about, and if you make it as 3 general as one interpretation of your proposal would have it, everybody shall have his rights. If that is all it means, 5 then it is so self-evident that it does not really need a formal preparation. 7

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DR. COOKE: Yes, but what I am trying to do is to 8 set up a situation where we can begin to list the conditions 9 under which it would be appropriate, providing, for example, 10 true vulnerableness does exist, providing there is -- I 11 hate to bring it up, but concordance, that is that there are 12 non-prisoners who are participating, providing there is an 13 opportunity for this, providing -- and it is these provisions 14 that I think we can come to grips with. 15

DR. RYAN: Excuse me. If that is what you are 16 getting at, why don't we find out from the Commission whether 17 we want to get involved in that kind of an exercise. I mean 18 really the question is, are you going to stop prison research 19 or are you going to allow it to occur under conditions in 20 which you feel prisoner rights can be safeguarded. 21

If the latter is worth the Commission's time, then 22 let us get busy trying to decide whether or not we can 23 create an environment where we would make a recommendation 24 to the Secretary that he can ethically support and conduct â 25

research, and I, personally, would suggest that the Commission try that. Everything I have heard about research, up until now, suggests that except for some very bad experiences 20 years ago and 15 years ago, and I am sure they still exist, I have not seen very many bad things going on in biomedical research. It has been indicated it is Phase I testing. The risk is small. We have papers with respect to the risk.

We all know that prison life is coercive, and we Q know that there are many things that are going on in prisons 10 that are a heck of a lot worse than their being allowed to 11 volunteer for research, that probably should take precedence 12 in society's concern even, but we have to deal with the 13 research. 14

So given that, and given that everyone around 15 this table feels that prisoners have rights, they are going 16 to have to decide whether this is one they should be able to 17 exercise, I would say that we could most profitably spend our 18 time, if we are of a mind about this trying to come up with 19 an accreditation process and make specific recommendations. 20 Even if it stops prison research because no prison can meet 21 those recommendations, I would sooner go that way than to be 22 completely negative. That is my position. 23 Now, if you agree with that, could we translate ä 24 ⁸ 25 that into a way of dialogue among ourselves so that we can

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1 put it into form? That is where I need help.

2 DR. STELLAR: I think Bob has got the answer, the 3 important answer to his question, and there is nobody on 4 the Commission present in the room who is willing to say that 5 we should agree to exclude prisoners from participation in 6 research.

7 MS. KING: No, that is not what you have. There 8 is one Commissioner, and I think we want to make this very 9 clear. There is at least one Commissioner in the room who 10 has got to hear all the conditions before she can reach a 11 decision about whether I would ask for a ban, and that is a 12 little bit different than asking me to vote on Bob's motion 13 now.

14 DR. RYAN: But I want to know if you want to hear those conditions? 15

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MS. KING: Absolutely. My decision depends upon 16 17 what kind of conditions we develop.

18 DR. RYAN: All right. Karen, please? 19 DR. LEBACQZ: I appreciate Bob's desire to begin with a very general statement about all human subjects and 20 move from there into talking about prison research, but I 21 22 think what has happened, Bob, is that you have got us hung 23 up on particular matters of terminology and language that are obfuscating rather than helping us at this point, and I 24 would like to ask you if you would be willing to think about 25

1 withdrawing your motion at this time with the understanding 2 that we might want to bring it back before us again later 3 so that we could begin the kind of discussion that Ken is suggesting that we do. I think you will have an easier time 5 of it later after we have talked about some of the other things, and if you don't withdraw it, then I am going to propose a substitute motion.

DR. RYAN: Will the seconder withdraw the motion, 9 whoever seconded it?

> (The seconder withdrew the motion.) DR. RYAN: Okay.

12 DR. SELDIN: Now, what about Stephen's proposal specifically in connection with prison research? In other 13 14 words, does the sentence of an individual to imprisonment 15 necessarily entail --

16 DR. RYAN: We don't have to beat that to death, 17 Don. The fact of the matter is it doesn't. We all know it 18 doesn't, except in the very real world when we test it. 19 It does not in principle, but what we have got to get on with 20 is whether we can test it. Can we, in the real world, set 21 up conditions which we would want to see met? Can we 22 satisfy ourselves that those conditions would allow 23 accreditation to take place and that surveillance would, in fact, go on and that rights would be protected and that the 25 public interest would be served?

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		. 158	and the second se	
	1	DR. SELDIN: I don't mind that, but there are people	nan an	
	2	who do think that in principle, with all due respect, one	and a second	1 at each of these arguments against
	3	should ban prison research on grounds that imprisonment		2 in research and to see whether or
	4	by its very nature precludes reasonable research. That is	and a first and a first a second s	3 prohibitions or whether they can h
	5	what they do in European countries. I don't think that the		4 DR. BRADY: That is what
	6	point that is being made is vacuous.		5 DR. COOKE: I think it i
	7	DR. RYAN: I know, but we were not having a good	an a	δ it plays into what we heard this π
	8	dialogue, and we were not making progress.	r	7 "guinea pig" was used. I believe
		DR. SELDIN: Okay. I know, but this is a much		8 good about research and noble abou
	9			9 terms that seem to me negative is
	10	more narrow and discrete thing than the more general form	1	0 doing, but nevertheless I think th
	11	that Bob phrased here.	1	1 think we ought to be talking about
	12	DR. RYAN: Dr. Jonsen?		2 rather prohibiting unless.
	13	DR. JONSEN: I will make a motion to get things	 	3 DR.RYAN: If you turn th
	14	started which I will withdraw immediately if it seems too		4 Dr. Jonsen's effort and turn it ar
	15	clumsy. My motion is that the Commission recommends to the	1	
	16	Secretary that no prison research be supported and that the		
	17	reasons for that are all of the reasons listed on page 78		6 but because the fact that prisons
	18	and 79. 1 put the question that way		7 should be, the accreditation, that
	19	DR. RYAN: Under paragraph B.	18	covers all of the input that we ha
	20	DR. JONSEN: Under paragraph B, with the intent that	19	P Commission could, in fact, embelli
	21	each of those questions be addressed and if we find any of	20) the conditions for accreditation.
40		the reasons or all of the reasons convincing we support the	21	Yes, Karen?
Control	22	recommendation, either reasons singularly or cumulatively.	Auguros 22	DR. LEBACQZ· I have an
keestina Compan	23		8 Bui	suggestion to Al's, and it would be
B. weis ker	24	DR. RYAN: I don't think that we need a motion for	10da 24	the first question on page 76, whe
() 90	25	that, but I think it might be worthwhile to go down and look	12M0g 25	in a form of consent and very spec
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ents against participation of prisoners whether or not they are absolute they can be --

hat is what I call the null hypothesis. think it is a bad form because to me neard this morning when the term I believe that there is something noble about research and to put it in egative is -- I know what you are I think the impact is wrong. I lking about allowing things providing

you turn the page you could take turn it around the other way and allowed because of these arguments at prisons are not as good as they ation, that is page 79 and 80 and it that we have had which the ct, embellish if it wanted to, including

I have an alternative procedural it would be that we begin by focusing age 76, whether the requirements are d very specifically that we begin by

looking at the requirements for informed consent as they 1 2 were laid out for us in the paper by Cornell West where there 2 3 are, I think, three principles elaborated, each one of which 3 4 has been addressed in one form or another by many of the 5 other essays that were submitted to the Commission, and it is 5 6 possible that in looking at these principles to see whether 6 indeed they are what is necessary for informed consent and 7 7 then whether the prison context is a context in which 8 8 9 each of these principles can be met that we might then be in a position to say what would be necessary in order for 10 10 research to be done in prison and whether indeed we think 11 11 under the present circumstances those conditions can be met. 12 12 13 That is a somewhat more narrow approach. 13 DR. RYAN: I would be willing to let you start 14 14 15 down that line, Karen, if yo_ nt to lead the way. 15 DR. LEBACQZ: There may be other Commissioners 16 16 who don't want to proceed in that fashion. 17 -17 18 DR. RYAN: I think that we have got to stop that 18 game. I mean, please start. I don't think that informed 19 19 consent is the only issue, but I think informed consent is 20 20 one, and it is of great essential focus. Why don't you 21 21 22 start there, since you have those things in front of you 22 23 and see how far it gets us, please? 23 2 Sep DR. LEBACQZ: Okay. I will begin with this because 24 Se Se 24 25 I found this paper quite compelling in some respects, although \$ 25

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equality and rationality. I think that that is fairly closely linked with what, indeed, the subgroup on ethical principles came up with at our last meeting. If freedom, equality and rationality are important premises for us, then Mr. West proposes that we should look for those principles which would be chosen by free rational persons under conditions of equality and fairness, and specifically he proposes that there would be three such principles. Let me see if I can get the exact wording on this. The first one, in essence, requires that someone be fully informed of what would be involved in research. The second one requires that a person openly consent, and the third one requires that an individual make the decision on rational grounds under conditions of equality and fairness. Those of you who have had a chance to read this essay will recall that Mr. West himself argues that prisoners can be fully informed and can openly consent, and he deals at length with the issue of coercion which has hung up our conversation at numerous points. I think we might do well to take a look at his argument at that point, but he argues that because of the nature of the prison setting at this

point in time that prisoners are not able to decide on rational

I think I have some disagreement with it at other points. As I understand the argument that is made by Cornell West, it is that we accept as basic premises of our society freedom,

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1grounds under conditions of equality and fairness and2therefore I assume would support a position that would allow3that research might be able to be done in prisons under some4circumstances but not under the present circumstances because5of the conditions of inequality and unfairness that exist6there at this time.7That seems to me to be a position that is very8similar to what many of us were trying to argue when we last9talked about this. Could we begin by looking at these10questions? We would be in a position to concretize the
therefore I assume would support a position that would allow that research might be able to be done in prisons under some circumstances but not under the present circumstances because of the conditions of inequality and unfairness that exist there at this time. That seems to me to be a position that is very similar to what many of us were trying to argue when we last talked about this. Could we begin by looking at these questions? We would be in a position to concretize the there at the sum of the present circumstances because of the conditions of inequality and unfairness that exist there at this time. That seems to me to be a position that is very similar to what many of us were trying to argue when we last questions? We would be in a position to concretize the the position to concretize the similar to what are the ground then is what are the ground then is what are the ground the position to concretize the the present can be free to the position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to concretize the the present can be free to position to position to concretize the the position to po
 that research might be able to be done in prisons under some circumstances but not under the present circumstances because of the conditions of inequality and unfairness that exist there at this time. That seems to me to be a position that is very similar to what many of us were trying to argue when we last talked about this. Could we begin by looking at these questions? We would be in a position to concretize the order to get benefits or action of the conditions of inequality and unfairness that exist threatened with having one coercion deals with threats talked about this. Could we begin by looking at these talked about this in a position to concretize the the similar to what are the ground
 4 circumstances but not under the present circumstances because 5 of the conditions of inequality and unfairness that exist 6 there at this time. 7 That seems to me to be a position that is very 8 similar to what many of us were trying to argue when we last 9 talked about this. Could we begin by looking at these 10 questions? We would be in a position to concretize the 4 threatened with having one to be a position to concretize the 4 threatened with having one to be a position to concretize the 4 threatened with having one to be a position to concretize the 4 threatened with having one to be a position to concretize the 10 then is what are the ground
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 6 there at this time. 7 That seems to me to be a position that is very 8 similar to what many of us were trying to argue when we last 9 talked about this. Could we begin by looking at these 10 questions? We would be in a position to concretize the 10 then is what are the ground
 7 That seems to me to be a position that is very 8 similar to what many of us were trying to argue when we last 9 talked about this. Could we begin by looking at these 10 questions? We would be in a position to concretize the 10 then is what are the ground
8 similar to what many of us were trying to argue when we last 9 talked about this. Could we begin by looking at these 10 questions? We would be in a position to concretize the 10 then is what are the ground
9 talked about this. Could we begin by looking at these 9 questions? We would be in a position to concretize the 10 questions? We would be in a position to concretize the 10 then is what are the ground
10 questions? We would be in a position to concretize the 10 then is what are the ground
10 then is what are the ground
11 discussion.
DR. RYAN: The things that don't exist are fairness 12 and fairness, and I think
13 and equality, and the question is can they ever be achieved 13 from what I understand of I
14 and must they be achieved and to what extent. 14 would argue that the condi-
DR. LEBACQZ: I think from my perspective there 15 not on grounds of equality
16 are two very significant questions that have to be addressed 16 they deal in the prison set
<pre>17 here. One is the question of whether indeed prisoners can 17 for giving consent are under 18 for giving consent are under 19 for giving consent are un</pre>
18 give consent, and I have argued previously that that is not
'9 to my way of thinking the critical question here. I think
20 this essay is in some support of my stand on that. He argues
20' issue like that, I think that indeed the conditions in a prison setting cannot be
$\frac{1}{2}$ 22 considered coercive in the loose sense in which we have
22 considered coercive in the loose sense in which we have 5 23 heard the argument about coerciveness but rather that the
24 conditions that have troubled us so much, the scale of payment g
\$ 24 you are going to allow res
[§] 25 along the way.

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research setting a condition t is one is being induced in ges. One is not being e situation made worse, and with a worsening of one's with inducements and the ms.

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etting is not coercive, he we, What becomes critical which one consents? Are they wen in a freedom of equality e, as well as John Irwin, say and several others, are such that prisoners are airness with those with whom and therefore the grounds d, but the consent itself se of that word.

me agreement on some kind of uld be very helpful for us.

t is the first step, Karen. response to that? I did with it. I think that it is, if in prisons the first step

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DR. LOUISELL: It may involve an oversimplistic ٦ rationalization of coercion in respect to bribery. Take, 2 for example, the person charged with a crime. We all 3 immediately acknowledge as self-evident that he is being coerced into a confession if he is beaten. However, if he 5 is bribed by being told that he will get a lighter sentence 6 if he will immediately confess, that is equally regarded as coercion, even though superficially it would appear under 8 this distinction to be mere bribery. 9

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DR. RYAN: I think he was trying to make a value 10 judgment using those two words as a degree of evil, perhaps 11 and not necessarily saying that bribery either for aircraft 12 companies or in prisons was acceptable. I think that in point 13 of fact what we have to decide, if we are going to take the 14 line that under certain circumstances research in this 15 setting is permissible, it is possible, what we are going to 16 have to decide is how to get the equality, how to get the 17 fairness, how to get the bribery portion into a very onerous 18 situation for the mother who promises favors for her child 19 if he does something good. We consider that bribery, but 20 it is a socially valued bribery if you will or may be. 21

That is why I think it is so important to look at the accreditation concept. If you, in fact, reduce research, biomedical research, to only one of many opportunities for prisoners to occupy their time and to do gainful things while they are in prison, if it is only one of many, and they can make a free choice among those, and it is felt desirable for them to be gainfully occupied, then you are in an entirely different context.

When the research because of the money pay or 5 because of the onerous nature of all the other opportunities afforded to prisoners is made to be the only one, and so in that sense that bribery is considered more evil than the bribery of offering money for a whole range of things so that people will be able to better their conditions. 10 DR. LOUISELL: I think that is very true, and my 11 major point is that we don't discount unduly the notion 12 of bribery as being an element of coercion. Take, for 13 example, what we saw at Jackson, those extremely attractive 14 clinics in contrast to the harsh prison environment otherwise, 15 the fact they then get the hope of reasonable medical service 16 for their personal needs by having that kind of affiliation. 17 That would loosely be called, I suppose, bribery, but it 18 becomes a serious factor on the question of whether they are 19 really being coerced by the environment into the submission 20 to the research. 21

DR. RYAN: Dr. Seldin is quite anxious to --DR. SELDIN: Well, I am not that anxious. DR. RYAN: Someone else? DR. SELDIN: But I do want to endorse your motion

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that we might consider starting from the point of view of accreditation. What is disconcerting about the prison is its setting.

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Now, research is always done in special settings. 4 Hospitals are a special setting, and often have a coercive 5 element in some subtle sense to it. So, is the doctor's 6 office, as has been pointed out, a kind of coercive setting, 7 and a prison might be more so, a coercive setting. Don't 8 misunderstand. I am not minimizing the setting. I merely want to emphasize that there is nothing unique about the 10 setting imparting a certain element of coercion, of putting 11 a boundary on freedom in some metaphysical sense of the 12 term onto the business. 13

Now, what we have to satisfy ourselves before we 14 go into the matter, I think, of informed consent is can we 15 somehow assure ourselves that the setting of the prison under 16 certain circumstances can be reasonable enough so that other 17 things, such as coercion, informed consent can be meaningfully 18 given quite irrespective of whether the prisoner conceives 19 it so. Now, if we can satisfy ourselves that accreditation 20 to a prison no less than to a hospital or to a doctor's 21 office can be described in some way which gives us confidence 22 that it is hollow, that we really do have protective safequare 23 that these safeguards are not transgressed, we can then look 24 to those criteria which would allow us to say that this a 25

prisoner within a wholesome setting, wholesome from the point of view of research, let us say, can give informed consent and it not coerced. So, I would like to suggest 3 more or less in line with your proposal that we consider 4 whether we can specify criteria for accreditation. They are 5 listed, and maybe we can elaborate however we wish, and 6 then if we satisfy ourselves we can look at the problem that 7 Karen raises of informed consent and coercion, bribery and 8 9 the like.

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10 DR. RYAN: I really think that it would be profitable if the Commission members are agreed, to get 11 the staff working and get ourselves working thinking about 12 the conditions under which this might occur to set those 13 conditions down and then ask the question now, are you going 14 to allow research. For example, committees composed of 15 prisoners, composed of outside groups that are sponsors of 16 prisoners, ACLU, if you will, or any other group and the 17 requirement that the government makes that there be set 18 inspections that there in fact be monthly meetings with 19 minutes being kept and so on and so forth. I think this 20 21 may create conditions in which research -- we would consider 22 research could go on, and I suspect, also, it might, in fact, 23 improve prisons in a way that people have not been able to 24 get them to improve otherwise, and if that is a secondary [₽] 25 gain so be it, but I thought that John Irwin changed his mind

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	1	so to speak or I should not say that. I think that what I	1	Then you just walk away. They stay, h
	2	read from his report was more or less a change of emphasis,	2	
	3	and he came out with recommendations I thought in that report	3	
	4	that were a little different than I perceived him telling us		
	5	when he first came with us. Is that true, John?	4	accepted which then go on and start t
	6	DR. IRWIN: Somewhat, somewhat. I got caught in a	5	the prison situation, and there are d
	7	trap where I had to abandon a certain set of values because	6	Prisons are variable and changeable,
		of feeling that I had to speak as an advocate for certain	7	impact on them.
	₩ 8		8	DR. BRADY: It is called do:
	9	groups of prisoners. I was finally able to solve this	9	DR. JONSEN: Mr. Chairman, r
	10	conflict in the manner which psychologists call cognitive	10	papers that we have received and of mu
	11	dissonance or they finally bring their old values together	1. 11	
	12	with new values and so on, and I now think that I am a firm		is that the strongest trend is toward
	13	believer in my present stand.	12	suggestion. I have not analyzed every
	14	DR. RYAN: I would commend to the Commission members	13	but that is the way it seems to me, th
	15	to read his report because it helped me.	14	few people who have said absolutely no
		DR.IRWIN: Just in closing, the strong part of	15	knowledge said absolutely yes, but the
	16		16	critics that seems to come down on the
	17	this new posture, the one that you just mentioned, Dr. Ryan,	17	If that is the case, I guess there are
	18	is in fact a chance here of not only making behavioral	18	of a moratorium. One is simply to gai
	19	research in prisons or biomedical research in prisons		
	20	acceptable but also having a general ability to impact on the	19	what is going on, and the other is to
	21	prison setting. I think the Commission would be remiss if	20	of a moratorium something constructive
Jup	22	they set the standards so idealistic that we, in fact,	21	tests for the activity under scrutiny
Compi		precipitated total abandonment of the stuff and then you	fund 22	just wonder if we might think in terms
Reporting Company	23		o 23	which is a constructive moratorium and
BOWEIS RED	24	walk away from the prison. You say, "Prisons are too	iodaa 24	a number of questions that we might as
BOM	25	horrible because therefore we cannot allow drug research."	ang 25	task force of some sort that would wor
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y horrible. It seems to me of conditions which may be have a chance of being the motion for improving e definitely changes.

doing well by doing good. , my impression of the much of the testimony rd the moratorium erything in great detail,

that there are relatively no, and nobody to my there is a range of the moratorium side. are two ways of conceiving gain information about to attempt in the period ive whereby some realistic hy can be devised. I rms of a moratorium and set up a device whereby ask could be put to a york in some area to see

170 whether it is, in fact, possible for prisons to live up to ŀ our criteria. 2 2 DR. BRADY: I would be against that. I think we 3 prison which has been called the best maximum security 3 ought to specify what the conditions are and then determine 4 4 whether there is anyone who meets the conditions. If there 5 5 are not, then I think we talk about a moratorium. 6 DR. JONSEN: That is not what I mean, Joe. 7 DR. BRADY: I am not convinced that it is necessary 8 to call a moratorium in all cases under all conditions. 9 prison, and I am kind of opposed to getting into real DR. RYAN: Pat King and Eliot? 10 10 specifics. MS. KING: I find myself a little bit opposed, not 11 11 completely to what Joe just said, but somewhat. I don't 12 12 think any of us are penologists, criminologists or have had 13 13 any vast experience with prisons or jails or anything else, 14 14 and the best that we could do would be to deal with a general 15 15 duplicate their mistakes. set of critéria that we consider standards that should be 16 16 DR. RYAN: I know. met in order to allow research to go on within a prison. 17 17 If we attempt to go beyond that, and maybe this is not what 18 18 you were saying, Joe, if we attempt to go beyond that, I 19 19 think that we are way over our heads, because we just don't 20 20 the other. I think that the thing is that we are coming know what we are talking about and that there is something 21 21 down on the concept that we might try and see whether Jup to what Al says in that some of the general standards may not 22 22 be enough and it may take a group of people who have far more 23 23 expertise than we do to come up with some more specialized 24 2 24 standards on this general base which may have to be trial 80M 25 25

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tested or it may have to be put into implementation, but I, for one, have lots of problems based upon the visit to one prison in the country and the worst, depending upon who you are talking to and one visit to Marquette and come out and think that I am such an expert that I can now start setting out more than general kinds of standards that I think have come to me over a period of time in terms of accrediting the

DR. RYAN: Pat, I would submit to you that some of the people who are writing laws on this have never gone and talked to prisoners according to the prisoners themselves. MS. KING: That does not say that I have to

DR. BRADY: By voting the moratorium you are presuming just the expertise which you said you did not have. DR. RYAN: Excuse me. We don't have to do one or conditions could be drawn, that we could then, as Al agreed to, was not different from his opinion to see whether any extant programs, and we could make this a requirement of the Secretary, to see whether any of the programs met those

1 standards. If not, research could not go on until they
2 did, but I think we have to start somewhere with respect to
3 that.

DR. STELLAR: I would like to see us take this 4 more positive approach, holding the moratorium idea in 5 abeyance if the standards are not met, but at the same time 6 I would like to see us following John's idea to try to phase 7 in the standards in some realistic way. I think if we set 8 them too high, initially then I think we will be defeating 9 the purpose we may have. Furthermore, I think that if we 10 set them too low we will also be defeating it. Therefore, 11 we have to, it seems to me, plan an elevation of the 12 standards to meet our ideals over some reasonable time 13 schedule. 14

15 I don't know what that is going to be or who can 16 give us advice on it.

DR. IRWIN: May I suggest something here? It 17 seems to me that setting certain kinds of standards is very 18 important, but more important is establishment of a 19 mechanism which in itself is a standard adjusting mechanism 20 which escalates the standards as time goes on because there 21 are a lot of coercive facets to the prison world that we will 22 not become sensitive to for years or which have not even 23 emerged which will emerge in future, years which have to be 24 addressed, and the only way to take care of it is the 25

establishment of a process.

2 DR. RYAN: What I would like to do is allow everyone to have a cup of coffee and then come back for a 3 final shot at that this afternoon. Do you want to say 4 something before the coffee? 5 DR. TOULMIN: Could I say something very quickly. 6 It does seem to me there is a great danger that the 7 Commission may set itself the task of rewriting Samuel 8 Butler's Erehwon. I say this having the following in mind. • • 10 I do think Karen was right to say that Cornell West's paper 11 sets a benchmark which represents one position we might 12 adopt, and I think he challenges us with the remark that 13 the real question is whether conditions of fairness and 14 equality which are requisite could conceivably be met 15 within prisons.

Now, before we go on looking at this in detail, 16 17 there is one other fact which I think our staff researchers 18 have brought to light which we should not overlook, especially 19 if we are going to start making pragmatist remarks of the kind that John and Eliot have been making. The question of 20 whether fairness and equality of a sufficient kind can exist in any prison is a question which necessarily involves 22 judgment. This same judgment has been exercised in a large 23 \$ 24 number of other countries, including all those countries a 25 with which we in the United States, we Americans would like to

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compare ourselves.

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In all of those other countries the decision has 2 been that the situation is that they do not do research in prison. If we were wanting to justify taking a short way with this issue, we could appeal to what is commonly known as the decent opinion of mankind and we should not forget this. In taking the accreditation road we should not forget 7 this.

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DR. RYAN: I want to put that in context, and I 9 don't want to be misquoted because I have said it before, 10 but there are certain countries, I am certain, where research 11 is not countenanced in prison where it has been said that 12 torture occurs, and I think that we should keep things in the 13 proper perspective. 14

DR. TOULMIN: But I think if we are going to work 15 out a procedure for making research in prisons acceptable, 16 it should be clear that the kind of reform that we are 17 contemplating is one which takes us, so to say, far syond 18 the best that people in other countries have been able to 19 manage. 20

DR. LOUISELL: It would be helpful to me, at least, 21 if we could have, after the break a little more explication 22 of why these European countries, and I take it it really 23 refers in general to all of the Western European countries, 24 why have they reached a conclusion despite the engagement 25

of some of them on occasion at least, in torture, why have they reached this conclusion in respect to research? DR. SELDIN: Because the spectre of Nuremburg is behind that.

DR. RYAN: Reconvene in 10 minutes. 5 (Brief recess.) 6 DR. RYAN: We have a lot of material to cover 7 over the next day, and I would hope that we can get most of 8 our work done. I would like to start now and just announce Q for the record that for the rest of the meeting Mr. Yesley 10 is the federal officer, and we can continue with our discussion 11 now of prison research. 12

Bob, do you want to lead off or try again? 13 DR. COOKE: Yes, let me see. I was trying to say 14 what I would hope we could do. From hearing Tannenbaum's 1.5 report, from looking at the, what I would have to consider 16 the relatively high voluntariness level of consent that we 17 would draw from his data and from some of our own observations 18 and I will try to amplify in a minute. I think the situation 19 is not as bad as has been made out, and I would think that 20 we ought to take the position that biomedical research should continue and that we ought to work to improve the protection, and there are some specific ways that have been suggested that might permit us to make improvements. Now, much of the

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prohibition against prisoner research, as far as I can see 7 has been based upon the "coercive" nature of the prisons 2 that interferes with what I would call voluntary consent 3 using the lead from one of our essays that says the consent 4 part of informed consent relates to information, and that 5 informed consent is a poor term in a sense because what we 6 are really talking about is voluntary consent, the 7 voluntariness of the situation being important, is well as 8 the information. 0

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Now the information side of the consent in the 10 prisons we heard had some -- could be improved some. We 11 heard that the forms were kind of confusing at times, et 12 cetera, but it did not seem to me to be a lot worse in the 13 prison setting than other places. 14

The voluntariness side, it seems to me the evidence 15 is quite good that individuals who have the most choice in the 16 prison environments, the most freedom of choice are the ones 17 that are signing up for research activities and the coercive 18 nature of prisons applies least to this group, that is they 19 are the people who are the sort of trustees. They are the 20 people that have the jobs. They are the people that have the 21 money so that the bare necessities of life are not being 22 provided by the prison research. The extreme deprivation 23 that some prisoners might have, those are not the group that 24 are in the prison research and so forth. Now, to my mind, the 25

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is no question that prison environments are not perfect by any means, but I don't think the situation seems now to be quite as bad, and I think it is very unreal for this Commission and I felt that way all along, we are not a Commission on prison reform, to attempt to reform the prison system by way of biomedical research. So, I would like to see us try to recognize the fact that research is ongoing, that it is not as serious an exclusion of voluntariness as may have been portrayed, that the burden is not being borne disproportionately in the prisons at least by minority groups and that we attempt to develop some mechanisms for improvement rather than throwing the whole thing out. DR. RYAN: Karen? 13

DR. LEBACOZ: I do disagree with you, Bob, but at 14 the moment I am not going to speak to my general disagreement. 15 I just want to clarify one thing that you said because I think that you have drawn a conclusion that is unfounded on the basis of some of the data that was presented to us. The fact that the people who participate in research also often hold paid positions in some other kind of work in a prison does not necessarily mean that they are the least coerced, if you will, or that they are more advantaged than other prisoners. It could be that they are the most desperate for money. 24

Until I knew what their financial obligations were,

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	1	whether they were supporting families or other outside sources			
	2	of income they had I could not draw that conclusion. I don't		2	
	3	want to see us begin to say that because we now have this		. 3	
	4	data that says that these people have higher educational		4	
	5	levels and that they also work in prisons that therefore		5	
•	6	they are not in some way in need or being induced by the		6	
	7	bribery elements or coerced by the coercive elements		7	a president and a state of the
	8	DR. COOKE: I said nothing about the bribery	· · ·	8 8	
	9	element. I am not talking about the bribery element. The		9. 9	-
	10	bare necessities of life, the toothbrush, the soap and so		10	
	11	forth, that group is least likely to be deprived of that		11	
	12	if they are already working, if they are already in the more		12	
	13	favored status group of that institution.		13	
	14	DR. LEBACQZ: You really cannot say that without		14	
	15	a lot more data than we now have about what other financial		15	
	16	obligations they have. I have been very impressed by the		16	
	17	large number of inmates who are working in order to support		17	
	18	families on the outside, and I just don't think that we can		18	
	19	draw that conclusion.		19	
	20	I am not drawing an alternative conclusion. I am		20	
	21	just saying that I don't think you can draw that conclusion.		21	
pany	22	DR. RYAN: Pat King?	4 ⁰	22	
ng Com	23	MS. KING: I don't know where to go except to	- Contraction	23	
Заметь Reporting Company	24	express disagreement with Bob Cooke, and I am not sure that	portir	24	
Bowers	25	that gets us anywhere. I would really prefer as a suggestion	wers	25	

because it seems to me to be the most fruitful avenue to explore of the two that I heard so far is to go back to Karen's suggestion which has some difficulties in it, but I am willing to overlook the semantic difficulties I discovered in it because I think it synthesizes the primary issue and that is and I will not use the term "informed" consent -are there conditions present in the prison itself which are or can be made to be fair enough to satisfy our concerns about equality, people who are outside prison, so that we would want to permit research to go on in those prisons. We can continue that avenue because I don't really think that there is anybody in the room, and I may be wrong who thinks research is an evil, that in the abstract that even research because it is done in a prison is an evil. I think that what we are mostly concerned about is when we put a research setting in a prison, what have we done with respect to the people who then become the subjects and are inside the prison. So, I think that most of us are trying in some way to preserve research, not destroy it and are genuinely disturbed by the fact that we are not sure we may be able to do it.

If there is anything that is troubling people, I think that is what it is, not that we are anti-research or not that we want to do away with research. The second avenue I heard suggested today which would

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give us additional information and certainly would be 1 2 informative to me, and I offer it as an alternative suggestion 3 is guys like David Louisell and Steve Toulmin both suggested and both were concerned about the fact that many European 4 countries with whom we consider ourselves and measure ourselves 5 by for all other sorts of activity have chosen to ban research 6 in prisons. 7

Now, it may be that that is because of the spectre 8 Q of Nuremburg, but there may be something about that very spectre of Nuremburg that we perhaps should be more aware of 10 11 because we were not in Europe, and I would suggest that either we get information about why European countries have chosen 12 to go a certain way -- it may be that their requirements for 13 testing of new drugs are not the same as our own. It may be 14 that they could not possibly continue their ban under our 15 kinds of regulations. That is fine. We need to pursue it 16 one way or the other, but at least I am suggesting that one 17 of those two avenues might be more fruitful in advancing 18 the discussion, and I leave it to the Commission to come up 19 with another or pick one of those two. 20

DR. RYAN: Some of that information has been 21 supplied in the report that was sent to us. 22

MS. KING: We can either discuss that or go back 23 to what Karen was suggesting. da 2 24

DR. RYAN: Dr. Seldin?

DR. SELDIN: I would like to make a try at this 1 once more. It is somewhat repetitive, but this is the last time I will inflict it on anybody. It seems to me that a prison describes three elements which ought to be taken into consideration in any formulation of prison research. One is that it consists after all of prisoners. It consists of a certain geographic confinement, and it consists of certain types of institutional arrangements. Now, from the point of view of research there is nothing particularly about the prisons that gives concern. It just from the point of view 10 of research. No one is claiming that they are insane. No 11 one is claiming that they are in principle irrational. No 12 one is claiming that they are infants or otherwise incapable 13 of making a judgment. The real problem about the prison 14 concerns an institutional arrangement within a setting of 15 geographic confinement which screens it off from scrutiny 16 from the rest of society. Therefore the arrangements of 17 informed consent and the like may not be creditable, even though one has the form which seems to be an acceptable form. If one wanted to, therefore, permit research to proceed in prisons, one would have to deal with the problem of insuring not merely a protection for prisoners but that this type of protection was not simply a surface phenomenon designed to place a veneer on the program but something real, something thatone could live with with dignity. I want to suggest

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1 that there are two ways of at least exploring this. One is 2 by a system of accreditation. Now, this could be graduated. 3 I realize that the term accreditation by itself is vague, but 4 still one could specify certain minimum conditions without 5 which no prison research could proceed.

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Now, I don't think by itself this would be 6 satisfactory alone. The second ingredient that I would 7 suppose should be considered is a system of surveillance. 8 Now, I consider this very important because the major problem 9 about prisons is the fact that it is a kind of very tightly 10 closed society, screened off from the public scrutiny where 11 you cannot trust anything in a certain sense. So, the 12 surveillance mechanism would have to be conducted in a way 13 which would be creditable. This kind of surveillance, to my 14 mind, could only be insured if the groups who participate 15 in the surveillance are those whom we might have confidence 16 with and who would be competent to make a judgment. 17 This would consist not only of the prisoners

This would consist not only of the prisoners themselves but groups who represent the prisoners and the interests of prisoners.

Now, if one could specify appropriate accreditation procedures and surveillances, then it seems to me that one would at least be in a position to judge whether other qualities, such as Karen mentioned and others have mentioned could be satisfied, could be reasonably satisfied. We

recognize that there are other institutional arrangements in which research is allowed to proceed which are by no means 2 coercion free. I am referring to a doctor's office, for example, or a hospital or special hospitals. I recognize that these are different institutions to be sure from a prison .5 where the state is the instrument of coercion, but I would, 6 therefore say that that is why one wants to specify more 7 rigidly procedures of accreditation and surveillance. I 8 just want to make one final point that has to do with a 9 hysterical addendum. 10

When I used the term "Nuremburg" before, this was 11 simply a summary label to embrace the Nazi and Russian 12 concentration camps which were such a horrible spectre 13 before the world and which one might feel was one end of the 14 spectrum of the prison confinement model. The other end of 15 the spectrum might be a very enlightened prison which, let us 16 17 say, only exists in model form, but we shouldn't imagine that all prisons are necessarily like that or that prisons 18 in the United States need be like that or one could not 19 break into this confined atmosphere by the procedures that 20 I mentioned. 21

What I would like to propose is this, as a formal way to get started, but as I say, it may not be acceptable. One is to see if we could not agree, if one wished to proceed in this manner, with appropriate accreditation and surveillance

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] procedures and see what we come up with, and then we can take 2 a look. Is equality or fairness reasonably satisfied by that, 3 and if it is not, through it out, but if it is, one would 4 have a way to begin.

5 DR. RYAN: Okay, Stephen, do you want to --6 DR. TOULMIN: I just want to make one last attempt, 7 after which I will shut up. I just want to make one last 8 attempt to state the general case for the negative a little 9 more strongly, and I want to follow immediately on John's 10 analysis. It seems to me that what is distinctive about a 11 prison is not merely that it is screened off from public 12 view, a closed community. In addition, one essential feature 13 of a prison is that there is a social distinction within 14 the prison between the jailed and the jailers and that it is 15 essential to the situation that there have to be mechanisms by which the jailers keep control of the jail. 16

17 Now, as we saw very clearly at Jackson, and again I don't think this took great insight, one of the ways in 18 19 which control is maintained is by establishing a system of 20 great economic inequalities as between the different prisoner 21 within the prison, which inequalities work against the achievement of any kind of social solidarity within the body 22 of the inmates. What we find, not surprisingly, is that those 23 who are most successful in all other respects because they -24 a 25 are most intelligent and most experienced succeed also in

185 locating the places where the greatest financial rewards are to be procured and make their way there and succeed in 2 the economic competition to obtain these rewards-which 3 economic competition is itself,/part, one of the instruments of control.

Now, it is my belief or rather the argument I 6 wish to put forward is the argument that where you have 7 research in prison, access to the pool of research subjects 8 itself will always be a part of the mechanism of control ò by which the jailers maintain control over the jails, and 10 that it is an illusion to suppose that any set of accreditation 11 1 procedures or conditions laid down by outside bodies could 12 ever obviate that, or could ever be applied in a way which 13 protected the prisoners against the manipulation of the 14 research situation by the prison administration as one part 15 of their instruments for the control of the jail. 16 I don't wish to assert this or argue it. I present 17 it as an argument which it seems to me has to be answered 18 if you are going to recommend accreditation procedures 19 with a good conscience.

DR. SELDIN: I thought accreditation was 21 associated here with surveillance and part of the surveillance 22 program was designed specifically to meet this. When I 23 said geographic confinement, I also meant institutional 24 arrangements. Due cognizance is taken of the fact that the 2 25 1

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prison is after all a coercive structure, and it seems to me that recognizing just the point that you mentioned requires that there be a representation from the prisoners amongst the prison population so as to at least attempt to meet the issue you mentioned. Now, whether it can be met.

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6 DR. TOULMIN: I am sorry, Don, but I only thought7 it was worth spelling out.

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8 DR. RYAN: Excuse me. There are many people who 9 want to speak. I want to call on them in order, please. 10 Dr. Jonsen?

DR. JONSEN: I want to express agreement in large 11 part with Stephen's statement. I think that the data 12 presented to us today can be interpreted in that way, that 13 the people who participate in research are the people who 14 know their way around, who get control or are in fact given 15 control by the authorities and allowed to maintain it within 16 the institution. I don't think that structural feature of 17 prison life is ever going to be done away with or will any 18 surveillance make much difference in it except to correct 19 the most gross abuses, for example, allowing a prisoner 20 to be a secretary in an office who can simply choose his 21 friends for research and no others, things of that sort, but 22 I just want to suggest that in looking for criteria if we 23 are moving in this direction of surveillance standards and Rep 24 accreditation, I suggested some months ago -- I used the BOU 25

phrase approximation of the free-living state as a standard 2 for what I believe West is describing when he says, "Judgments 3 made in a condition of freedom and equality." Approximation is to be underlined precisely because you recognize that 4 5 there are certain structural features of prison life that you will never erase, but there are others that you can erase 6 or modify or ameliorate, and I would suggest that they are 8 the following, and these are areas where one might look for 9 standards in the modes of communication between those who 10 are inside and outside, in the modes of recourse and redress 11 which are open to those who are inside, the modes of 12 participation in decision making which exist, the modes of protection for those who are particularly at disadvantage 13 and the modes of alternative resources for maintaining one's 14 15 life.

It seemed to me those are some of the modes of 16 existence in a prison situation which can be examined, which 17 can be described in certain ways in terms of better or worse. 18 For example, prisoners have access to telephones or don't 19 and how often and under what circumstances, and if you 20 develop a picture of a prison in terms of those modes of 21 prison existence you might at least be able to spell out 22 an approximation, the way in which that prison approximates 23 the free-living state, and in those terms then say the 24 decisions made in such a situation are at least enough like ⁸ 25

the decisions that people make when they live freely that we could accept the possibility of research being done.

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DR. RYAN: John Irwin?

DR. IRWIN: It seems to me an awful lot of discussion is coming together and going along on a ground 5 which I find very, very acceptable according to my own 6 views. I would like to try to pull some of the strands 7 together. I am in total agreement, Al, with your identifying 8 those facets of freedom which may be brought together 9 between the outside situation and the inside situation. I 10 think that they do address the conditions that Cornell West 11 laid down in his paper. I wanted to see if we could not use 12 it as a standard. It seems to me that the way we have to 13 approach that, the values of freedom, and fairness and 14 equality, certain levels of this have to be reached in order 15 for it to be permissible. We have to admit that inherent, 16 essential, explicit in the prison situation is that there 17 is in some areas a reduction in equality, a reduction in 18 freedom. We must identify which ones of those are essential. 19 We know that beyond the ones that are essential 20 society really intends to reduce, the prisoner should not 21 have the same freedom to travel to the Riviera or whatever 22 and that is intrinsic. That is inherent in imprisoning 23 people for punishment, but within those sets of things 24 explicitly intended to reduce freedom we should defend that 25

there are many other areas or all other areas, I would submit that equality to the degree to which it is consistent with a system of incarceration should be maintained, and we could do that. I think we can specify a lot of those, and we can start approaching those.

Now, we know that the prison system itself as all 6 organizations, loves to fall in or tends to fall into practices 7 at their convenience and therefore they obtrude into those 8 other areas. They start restricting other areas of freedom 9 which are really not necessary to maintaining incarceration, 10 but all bureaucracies tend to do that, all organizations 11 which particularly if they tend to be authoritarian, and 12 particularly if they tend to operate with a high degree of 13 autonomy which is the case with the prison. It is probably 14 the most autonomous, the most hidden organization in our 15 society, and it has gone quite far operating that way, and 16 it is also true that there is an informal system of control 17 in which certain privileges prisoners are encouraged to 18 aid in the maintaining of control. One of the papers 19 addresses that, Jack Sussman's paper. 20 However, I don't think that those are insurmountable

However, I don't think that those are insurmountable problems. I think that in really addressing those directly which I think you have done to a great extent, Al, I think that you are identifying the two kinds of general attacks which have to be made is the proper direction. I would suggest

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	. 1	one correction, surveillance I would like to see you shift	
	2	to the concept and the label of review and grievance	2
	3	mechanism which suggests something kind of different.	
	4	Surveillance, also, on the one hand, the prison people will	4
	5	feel that there is this overseeing their operation, whereas	5
	6	review and a grievance mechanism has a different connotation	6
	7	and also a different mode of operation which I think has a	7
	8	chance of being more successful. I think that those will get	8
	9	at trying to expand the level of fairness and equality and	9
	10	freedom in all those areas in which it is not essential	10
	11	for maintaining a system of punishment.	11
	12	DR. RYAN: Ms. Height?	12
	13	MS. HEIGHT: I think related to this, it seems to	13
	14	me that we for our own credibility of what we are going to	14
	15	say if we come to a thing like accreditation would have to be	15
	16	very clear on the whole point that there really is a large	16
	17	body of both documentation, as well as opinion about the	17
	18	need for complete change in the prison system, so that what	18
	19	we are recommending does not seem to be a way simply of	19
	20	bolstering up a system that works for some but not for all,	20
	21	and it seems to me that I would hope that we could get	21
Nupany	22	through this some of the information that we could use to	
Bowers Reporting Company	23	support that.	لی 22 میں 23 کی 24
zrs Repo	24	We have had some groups even saying, "Abolish the	
BOW	25	prisons." I am not going that far. It seems to me we would	signed DE

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need to certainly put whatever we are going to say within the context that we are not really just seeing something happening within that system but we are recognizing inherent injustice, I would say, but this group may not wish to say that within the prison system.

The second point it seems to me, when we were talking earlier about excluding the prison population, the point that I would hope we would say we would not talk about excluding because that again seems like it is somebody deciding for someone else, but I think that the crucial point there is the excluding of the opportunity to participate which keeps the individual right to speak for him or herself at the heart of it. It seems to me that that is a simple phrase, but I think it always has to go with it or else we will find people saying, "We are not excluding, we are including you," which is exactly what some people don't want to have happen. They want to have the right to determine whether they will se included.

It seems to me that that is another kind of basic condition that we need to work on and work for. DR. RYAN: Bob? DR. COOKE: Now, I guess I am taking a different perspective from everyone else, but it seems to me the title ¹/₂ 25 of this Commission is the Protection of Human Subjects who

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are used in biomedical and behavior research.

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Now, I agree that the prisons are an unfair place, 2 and I think they are terrible and ought to be replaced by 3 other mechanisms and I am sure there are a lot better ways 4 of doing what prisons are trying to do than the prison 5 situation. So, the fact that fairness may not exist in 6 prisons is to me not necessarily germane to the argument 7 regarding the protection of human subjects. What I am 8 concerned about is whether or not the subjects who are in 9 biomedical research are indeed given -- they have had an 10 opportunity to make a voluntary informed choice. Now, the 11 weight of the evidence seems to me to be that these people 12 are those who are the subjects, actually have had a fairly 13 good opportunity, not as good as it might be, we might 14 improve on it, but they have not had too bad an opportunity 15 to make a choice. 16

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They are not the most coerced individuals in the 17 prison. They are individuals who -- now, you can say that 18 maybe they have got bigger families and so forth, but there 19 is absolutely no evidence that that group is that much 20 different from the other individuals in terms of financial 21 needs, et cetera, and my observations of th subjects who 22 are in the biomedical research unit, indeed they did have 23 more advantages personally. They had more advantages than 24 the other group. So, it seems to me that we ought to be 25

concerned with those who are in the research setting and how we can give them somewhat greater protection. The fact 2 that there may be some people in that prison who are not allowed to be subjects, that may be somewhat upsetting to people, but that is not our main job, to see that everybody 5 in our society can be a subject for research. I just don't want those people who are the subjects 7 to be discriminated against, and none of the arguments I 0 have heard have anything to do with that. DR. RYAN: Dr. Louisell? 10 DR. LOUISELL: I feel somehow compelled to test 11 some of these very cogent philosophical statements and I 12 refer particularly to Dr. Seldin's specific cases. Now, a 13 few weeks ago I think we were all shocked by the news item 14 in the paper and then over TB, and I see there is data 15 pertinent to it under Tab 7 here from the ERDA about the 16 experiments in Washington and Oregon prisons, I believe on 17 irradiation of genitals. 18 DR. BRADY: Walla Walla. 19 DR. LOUISELL: Walla Walla? Now, I am just 20 wondering how significantly is this experience to be taken. 21 It was a dramatic thing as I witnessed it over TV. Is it 22 to be taken as a freak experiment that we need not be, on a 23 general basis, overly concerned with or is it to be taken 24 as indicative of the perpetual perennial danger that surrounds ² 25

the prison environment.

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DR. SELDIN: Do you want me to respond?

DR. LOUISELL: I would be delighted to hear your explanation.

DR. SELDIN: In the first place, I would agree 5 with you completely. First of all, I would take the worst 6 view and say that it is indicative of the perpetual problem 7 in prison environments. Yes, I do think so. I think it is 8 just the ingredients that have been mentioned up to now, 0 secrecy, screening off from public scrutiny, internal 10 coercion and the like that permits this, and so if we were 11 to have appropriate safeguards to this, this should take 12 cognizance of the danger of this type of practice, particularly 13 in prisons. 14

I may point out that there is a certain danger of that in hospitals and a certain danger of that in doctors' offices as well, and there are many instances one could give of this sort of thing also.

19I don't want to press the point. I am not trying20to argue the extreme point that there is no difference21between prisons and these other institutional arrangements.22I merely want to say that it is a public institution, and if23it is to qualify for certain kinds of activity, there ought24to be devices which allow us to get into the prison in some25open manner. If this were not the case I would not do research

there.

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Now, whether we can devise a series of ground rules 2 embodying such things as accreditation I think you said, 3 reviewing grievances, whether we can have appropriate bodies sit on review and grievance committees, review and grievance, 5 whether we can have appropriate bodies sit on review and grievance committees of a kind that would give us confidence remains to be seen. Moreover, I don't think this should be viewed as an all or none principle. One can say that one would have probationary 10 periods. One would have rescrutinizing periods. If it turns 11 out that problems emerge despite these safeguards, I would 12 say abandon it. In short, I am pefectly willing to admit 13 that the kinds of appalling issues you cite do represent 14 one of the grave dangers inherent in any kind of miniature 15 closed society and the judgment we have to make is can we 16 erect appropriate safeguards. 17 DR. RYAN: Karen, please? 18 DR. LEBACQZ: Now, there are so many things on the 19 table before us that it is tempting to enter into a lengthy monologue and speak to them all. I want to make a couple of 21 quick points. One is an addition to the list that Al Jonsen 22 gave us of those kinds of conditions which would approximate 23 the free-living state and which might provide the grounds for 24 \$ 25 us to deliberate about what would be necessary in any kind of

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196 accreditation procedure. I am not sure that this was excluded from Al's list, but it was not stated as explicitly 2 as I think it would need to be.

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It seemed to me that one of the things that we hold very dear in our society, possibly more in the breech than in the actual practice, but nonetheless we hold it dear is freedom from arbitrary power over one's life to which we sometimes give the phrase due process. That seems to me a little different than simply talking about mechanisms for redress, and what I have in mind is, for example, the 10 difference between having a prisoner have a mechanism for redress after being thrown in the hole as opposed to having 12 to go through some kind of due process hearing before being 13 thrown in the hole, so that I would want to add to that list 14 some of the kinds of things that I think fall under that 15 general category of due process which I believe are covered 16 in some of the legislation that we heard about this morning in the report by the Boston University Center for Law and Health Sciences.

I want to raise another kind of procedural question here. I am not sure that Bob Cooke is yet satisfied that he has received an answer to his question. It is possible that the remainder of the Commission is of a mind to think that we need to move toward these kinds of accreditation procedures and that if Bob does not share that that we may

197 have to ask him to hold the minority position and to ---DR. COOKE: I am all for that, plus some more. 2 DR. LEBACQZ: Okay. Then you have a specific 3 question about why we have a concern about whether other people get into research and things like that. I would like to try to answer that concern of yours, Bob. I am not sure that I can convince you, but I will at least spell out to you my own thinking on that.

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My thinking on that is essentially this. It is 9 true that we heard data this morning that in some prisons 10 those who participate in research also hold other paid 11 positions within the prison. It is, also, true that one of 12 the institutions that several Commission members visited, 13 Vacaville Medical Facility in California is a 2000-bed 14 institution that has one industry with 50 physicians 15 available. 16

There are then some 1950 inmates of that 17 institution who do not have alternative work opportunities 18 available to them. Part of our concern, it seems to me is 19 whether then since they do not have alternatives available, 20 whether they really are in a position to enter into 21 research under what we would consider fair or equitable 22 or positions of equality in terms of their bargaining power. 23 They really have no other way to make money. Now, it is 24 not that we are trying to say that everybody should get into 25

research, but surely then those at Vacaville who do
participate in research might be said to do so under somewhat
constrained conditions. Part of our concern is what we need
to do in order to minimize those kinds of constraints, and
that is what I understand the accreditation movement to be
moving toward.

I would be one -- I am willing to participate in 7 the deliberations of the Commission as we go about setting 8 the standards for accreditation, and that is why I have 9 proposed one and added it, but I would be one who would be 10 willing to argue the position that Stephen Toulmin outlined 11 a moment ago that says, in point of fact that the power held 12 by the prison officials is so arbitrary and that surveillance 13 or review and grievance mechanisms will be so faulty that 14 indeed I might decide that it would never be possible to 15 move into the kind of accreditation and review mechanisms 16 that we might like to establish. I am nonetheless willing 17 to go about the initial process of trying to set them up, 18 but I do want to make the statement that I may end up 19 arguing that position which he so cogently outlined a few 20 moments ago. 21

DR. TOULMIN: May I add a footnote? I think we have now got to the point at which the most instructive thing to do would be to discuss what these conditions would have to be. My purpose in stating the case as I did was

simply to make sure that the Commissioners had it in mind what the target was that they would have to reach. If it 2 were possible to reach this target, if it were possible to satisfy ourselves that, as one of the contractors suggested, within the area of each federal appeal court there was a regional committee which had statutory responsibility for conducting this desirable kind of survey and we were 7 satisfied that they could be effective in their operation 8 and that their operation would not be subverted by the Q prison authorities then I think we would indeed have achieved 10 something. But I do feel the argument has now gotten to the 11 point at which it would be very useful to set down what 12 these conditions would have to be like and that we can 13 then appraise them. 14

15 DR. RYAN: Dorothy, did you have something? MS. HEIGHT: One other point that I have been 16 struggling with in this list that Al brought out, I think has 17 to do with something that is related to the population and 18 the administration. It seems to me that looking at 19 institutional life one has more of a chance of having a 20 sense of freedom within it if there is pluralistic governance 21 22 rather than if you have got as we have pretty much in the prison system in the United States you have one kind of group p 23 that is in charge and has predominance and others who are 2 24 \$ 25 in the inmate position. It seems to me there needs to be something

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	1	of this, and I think that is why I feel less hopeful about
	2	real change in the prison system, because if you go back
	3	through the same kinds of machinery the people who are
	4	administering and you have so built in a whole system of
	5	injustice, then bringing about change is not just a question
	6	of getting a new procedure or a new set of policies or a new
	7	set of standards. You then have the whole problem of how
	8	you get enough change to bring about change, and that is why
	9	I would hope we would think about something that has to do
	10	with a more pluralistic governance. In other words, I feel
	11	more at home if there is at least somebody who understands
	12	a little of what I say, and if you say one point and someone
	13	says, a guinea pig, it says one thing to one sort, and if
	14	we think one way it says another if we think another way,
	15	and you see there is a home in view that I find as we talk
	16	about the prison system that is so much like the community
	17	that we cannot just you know, we talk about redress, but
	18	you still have to go back through the same machinery, and
	19	you don't have more representativeness within those who are
	20	carrying responsibility. People have more sensitivity to
	21	what people are up against, then you will not have real
npany	22	change. So, I would think that one of the conditions that'
Bowers Reporting Company	23	we need to think about is basic change in the whole question
5 Report	24	of governance.
BOWER	25	DR. RYAN: Dr. Cooke?

DR. COOKE: Let me see if I can try this one. I have been through it before, but let us say that we cannot alter the prison system to make it a fair place, and I think that is a reasonable statement, because I agree with you all along the line. There is enough in the way of injustice 5 so that at least for my lifetime to have a prison setting where there was justice and fairness in it, maybe because the prisoners are not just and fair, maybe they have got a level of moral development that makes it very difficult and Q so forth, as well as the relationship with the caretakers 10 and relationship to the rest of society, but what if we 11 looked at each biomedical research project and say to ourselves 12 is this one -- has this one in some way operated fairly? 13 What sort of criteria would be required to be able to say 14 that in that particular situation fairness seemed to have 15 operated at least in terms of what the real world is and 13 outside world and so forth. Now, if you ask that question, 17 I would have to say that fairness would have operated in 18 regard to a minimum of coercion, if there are a lot of other 12 people in the non-prison world who are willing to get into 20 that same act as the prisoners, that is if we have got a 21 substantial number of non-prisoners who are saying for that 22 same amount of pay, that same degree of inconvenience, that 23 same amount of risk, et cetera, I am willing to throw my hat 24 in the ring and be a subject. Then should those prisoners who ² 25

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are agreeing under those circumstances not be considered to
 have made in a sense a kind of reasonably fair choice under
 reasonably fair circumstances?

That would mean then that we might permit research where other individuals who are non-prisoners would indeed be volunteer subjects for the same wage, et cetera as the prisoners.

Now, that ducks the issue of accreditation which 8 you may want to do for other reasons and so forth, but to me 9 it is more a part of the real world. I don't believe the 10 accreditation, as you do, is going to be able to look over 11 the shoulders as well in a closed environment, et cetera, but 12 if we have reasonable individuals agreeing to participate 13 in these protocols in settings which are concordant with the 14 settings of prisoners, then I think that might be considered 15 a fair test of equity and non-coercion and so forth. 16

DR. RYAN: Pat King?

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MS. KING: I would like to move the following. 18 I move the Commission defer for the time being the 19 consideration of narrowing our concerns to the research 20 setting in order to proceed with the discussion of the 21 possible development of accreditation modeling. If I can 22 get a second I will explain why I am doing it. I said, "For 23 the time being." Do I have a second? Anybody? 24 DR. LEBACQZ: I will second it. 25

MS. KING: I offer that motion because Bob may have something to the point that he is trying to stress, and 1 do not want to obscure that. I do think, however, the only way to evaluate a position effectively that he is trying to espouse is to see and have in opposition another 5 perspective fully developed, if we can do it. If we cannot do it, that may bring us to your way of thinking or it may 8 bring some people to your way of thinking, Bob. ò So, I would like to move, if it takes a vote to do 10 that, to defer that consideration and move on, and then if 11 that passes, I would offer a further motion that we then 12 proceed to take up Dr. Jonsen's suggestions one at a time 13 to see if we can give them any flesh. We may not be able to 14 do it. If we can do it, we have learned something. If we 15 cannot do it we have learned something, and that might be 16 valuable.

17DR. RYAN: I don't think we need a vote, Pat. I18think most of us feel that we are going to have to get on and19do that. I just want to call on the other two people who20wanted to speak and then ask Al to start out for us and go21down that road if it is all right with you, Pat.22Dr. Stellar?23DR. STELLAR: I would agree with what Pat has just

DR. STELLAR: I would agree with what Pat has just 24 said. It would help me though if in going down this list 25 we were careful in distinguishing what we mean as those standards

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which would apply to the research process and those which 1 I think maybe Dorothy and others also have in mind which 2 . 3 would apply to the general setting, not that we should neglect either one any more than the other, but if we keep them 4 separate in our thinking, then I think we can do a cleaner 5 job. 6

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DR. RYAN: I don't know, I may be wrong, but I 7 read the newspapers and watch the television, and it seems 8 to me that there is a whole revolution going on in the penal Q. system, at least in our state and so on. There is much more 10 openness. There is much more going on there. There is much 11 more concern about what goes on in the prison system, and 12 I think it is a time when they might be amenable to change. 13 There is just no question that they cannot do in prisons 14 things that they did previously without public scrutiny. 15 The press is more active. The prison groups are much more 16 active. Now, I don't think that we are to that perfect 17 world at this time, but I am not as pessimistic as some people 18 that society cannot make some changes in the system. 19

DR. LOUISELL: The courts are more active. 20 DR. RYAN: Yes, and what did they do in the State 21 of Georgia in which the --22

MS. KING: Alabama.

DR. RYAN: Alabama, I am sorry, in which they had 24 something to say about all of the state prisons, so that I thit 25

it would be helpful to go along the road that Pat is suggesting for us. John, do you want to add anything before that? Al, why don't you start. We are not going to go late into this evening. We will go perhaps another 30 minutes or so, but why don't you start with the things. The first one 5 you talked about was communication, but you know, that is a 6 theoretical thing. Let us put it into practical terms for 7 8 each one.

Can you relate communication inside and outside 9 into requirements within a prison? 10 DR. JONSEN: I would conceive of that in this way. 11 You begin by asking some questions about the ordinary modes 12 of communication, such as letters and telephone, and you 13 would ask questions like are prisoners permitted to write 14 letters or not. Are their letters censored or not censored? 15 Under what conditions are they censored? Do they have any 16 privileged mail? To whom does it go? 17 So, you develop a range of questions having to do 18 with letter writing. You develop a range of questions having 19 to do with the telephone. Do they have access to the phone, 20 under what conditions? Do they pay for it? Do they not, 21 et cetera? We found quite different practices in different 22 places in that respect. 23

You would have something about the flow of 24 information in, in the sense that do they have access to 25

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	1	magazines, books, newspapers, under what conditions, and		
	2	then you would talk about the communication that they might	and the second second	lawyer and that they have
	3	have with other individuals face to face, with attorneys,	n Ladian Stranger	2 committee's office at any
	4	which I guess is fairly clear in most places now, but with	Service of Physics of Service	3 Vacaville has reviewed tha
	5	prisoner help groups, with people who come in to do a variety	1991 (authorities. We do not ye
		of good works in the institution. What other kinds of	and over the state of an and	5 those kinds of provisions.
	6		() () () () () () () () () ()	The other side t
	7	communication?	Beringstation -	of public exposure, that is
44.	8	DR. RYAN: Of course, the essential thrust of that	2 2 2 2 2 2	prisoner in his own decisio
	9	kind of communication, aside that it is nice for someone	5	a window. So, my idea woul
	10	inside a prison to have that or humane or something, is that	10	
	11	if research was going on, it would not be able to be kept	11	
	12	from public scrutiny if the communication in and out was		
	13	free.	12	
	14	DR. JONSEN: That is right.	13	
	15	DR. RYAN: And uncensored, isn't that the	14	prisoner can get to a telep
	16	DR. JONSEN: Yes.	15	DR. RYAN: And if
		DR. RYAN: Essential ingredient?	16	uncensored mail and telepho
	17		17	committee, I don't think th
	18	DR. JONSEN: Yes, there are really two sides to it.	18	could countenance research
	19	One is that you are assuring that the conditions are such	19	DR. JONSEN: Yes.
	20	that volunteers have a flow of information to them and can,	20	DR. RYAN: Because
	21	in fact, get information out if they feel a need to. Let me	21	
npany	22	give you an example of that? Our committee at the University		
ng Cor	23	of California School of Medicine has asked Vacaville that	Com	DR. JONSEN: Anoth
Bowers Reporting Company	24	all prisoners who are research subjects have privileged	Buitrod	asked for there was that the
BOWERS	25	mail to the committee in the same way that they do their	ta 24	there is a prisoner. The he
	i		8 25	On the review body in the ur

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they have access by telephone to the the at any time, and the review body at viewed that, accepted it, passed it on to the do not yet have an answer. So, we have made

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er side to this would be precisely the side e, that is it is not only of value for the wn decision but also the fact that it opens idea would be that you would start to f questions about all of the modes of d then you try to work out some kind of you would say, "An institution where there vailable clearly ranks below one where a to a telephone when he needs it." N: And if he does not have privileged and telephone access to research advisory think there is anyone in this room that research under those conditions.

: Because he would then be a captive with e would be no scrutiny.

JONSEN: Another mode of communication that we was that the prisoner on the review body -soner. The head of the prisoners' council is body in the prison, that that prisoner have an

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	1	unhindered access to an outside medical adviser and that a		
	2	number of physicians in the community, and there is a	1 1	the courts have actually looked at
		university hospital there are to be given to that person on	a subsection of	DR. COOKE: Could you amp
	3	a list, and he can call up and talk directly to a disinterester	u de la compara de la compa	helps in the issue which seems to m
	4		4	keeps citing, why prisoners should
	5	outside physician which would be another mode of communication.	5	voluntary consent, how this gives g
	6	DR. RYAN: Does anyone have anything they want to	· ·	the consent?
	7	add to that, to that concept? It is probably one of the	and the second	I am not objecting to it,
	8	more fundamental ones.	na sidente la	to see how it fits in in that persp
	9	DR. COOKE: That is all after the fact kind of	suture a dete	
	10	though. That is the problem. That is after they are in it	the first of the	
	11	and so forth that there are problems.	10	
	12	DR. RYAN: No, when we are setting up an	1	something that is going on within t
		accrediting system we would say you just cannot do research	12	but rather refers to a description
	13	unless	1:	3 which those people move and that th
	14		14	judgments about voluntariness is to
	15	DR. COOKE: Okay. I see what you mean.	1.	5 their situation approximates what w
	16	DR. RYAN: This is what we are after.](free-living state.
	17	DR. LOUISELL: You have got to be very precise		DR. COOKE: Their meaning
	18	in the specification of the mail circumstances, and there		
	19	would have to be taken into account a decision of the		
	20	Supreme Court a term or two ago from California that was	1	
	21	quite a detailed consideration of rights to mail and to	2	
È		receive letters, the impinging necessity that certain	2	
Company	22	correspondence be subjected to at least x-ray tests for	funduno 2	2 be some differences. For example,
Reporting	23	dangerous instruments and so forth.	orting C	3 that for the general prison populat
ers Rep	24		s kepor	4 according to a rule of twice a week
Bowers	25	In other words, we cannot be aloof here from what	13 MOB 2	5 but you might also add to that that
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not be used, namely, greater voluntariness of

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n from which I am moving not a description of the heads of individuals, of the circumstances within ne best way to make o judge the way in which we would consider to be a

y the prisoners? The prisoners. Ean all prisoners then would

ight mean that there would you might be satisfied tion access to the telephone k is pretty satisfactory, t anyone who is, in fact,

presently in a protocol should have unlimited access when calling some designated parties. 2

DR. RYAN: Barbara Mishkin, please?

MS. MISHKIN: Yes. There was one element which 4 I think you all discussed last time which you might want to 5 add to your list and that is access of the accrediting body 6 7 or the IRB, one or the other, to relevant records in the 8 prison, to review relevant records.

DR. RYAN: Communication has to be two-way. You 9 have to know that the prisoner has the opportunity to do this. 10 You have no way of knowing whether he is exercising that if 11 you don't hear from him unless you go in and ask. 12

MS. MISHKIN: They might want to look at various 13 records, I don't know; and there were some questions last 14 time as to which would be relevant for this purpose. It is 15 another measure of openness. 16

DR. RYAN: Karen?

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DR. LEBACQZ: I have just a question that is along 18 the lines that Eliot proposed, and that is if you do intend 19 for these to be different from one setting to the other, that 20 is from the prison in general over to the specific research 21 setting, then I might need some more specification on that. 22 Another question is about access of other outside groups 23 to the prison itself. What you have talked about thus far, 24 I think, by and large, is access of prisoners to these other

groups so that a prisoner might have the right to get to a telephone to call somebody, but what about a sort of 2 generalized access of groups like the ACLU or some other 3 prisoners' rights group to the prison? Now, this may be moving us in the direction of 5 the review and grievance mechanisms rather than the actual standards, but it might, also, be very important. We might 7 want to decide that a prison which lets people from the 8 inside get out but nobody from the outside get in unless 9 they have been called specifically is not open enough. 10 I would argue that myself because it seems very clear to me that the only way that we have any reasonable hope of insuring that there is no arbitrary power being exercised within is to have outside groups having free access to get in and make sure that someone was not deprived

11 12 14 of their privilege to use the telephone. 16 17 You may get an assurance from the authority that 18 says, "Well, yes, of course, anyone who is in the research program can call such and such a number anytime they want," 19 but how are you going to know whether in point of fact they were allowed to use the phone when they asked to use it 21 22 unless there is some kind of openness in terms of a general -- so I would want something along that line, too. 23 24 DR. JONSEN: John Irwin can verify this, but I 25 understand that in many prisons now there is regular

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	1	allowance for certain kinds of prisoner help groups to be		
	2	present regularly in the prisons, to have an office into	1	body in which the prisoners are repre
	.3		2	do prisoners well, basically the
	4		3	would go along those lines. We must
	5		4	that.
	6	time being is to try to identify these concerns and then	5	DR.IRWIN. That would, under
	7	build on them later. I think we hear you, Karen. Barbara	6	be ability of inmates to organize.
	8	was referring to the same thing when she talked about the	7	DR. JONSEN: Yes.
	о Р	institutional review board, I think. So, you have defined	8	DR. RYAN: Yes?
	10	one way that we can test whether the environment is going to	9	DR. IRWIN: Al, the way we
	11	approach that that we are thinking about and that is the	10	these are two things we have been wor
	12	free flow of communication or the extent to which communication	11	three of these, the grievance mechani
	13	is allowed both in and out, and the next thing you talked	12	modes and the prisoner participation,
	14	about was recourse and redress.	13	in California to get acceptance of a
	15	DR. JONSEN: The order might not be the best order.	14	all three of those together. They do
	16	DR. RYAN: Take another one then.	15	type of inmate structure or participa
	17	DR. JONSEN: Maybe participation in decision making	16	it seems to me, is one that has acces
	18	would be a better one for the second.	17	or it is meaningless. Without that
	19	DR. RYAN: Yes.	18	outside affiliation to give it the ty
	20	DR. JONSEN: In that way you would start to specify	19	empowerment that it needs, that they o
	21	the way in which prisoners were part of certain structures	20	goes wrong or some legitimate question
Auo	22	whereby decisions were made. Is there a prisoners' council?	21	presented by the prisoners and is not
g Comp	23	How does it come into being? I am recognizing that all of	luc 22	outside group has a chance to try and
Reporting Company	24	these things may be heavily political and so forth, but	autro	get into court, the legislature, the m
Bowers	25	we are just asking a factual question. Is there a review	^{da} 24	done about it, if it is a legitimate p
			₫ 25	all tie together, as a matter of fact,

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presented? In what way e participation questions st be able to understand

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nder the staff recommendation,

e are working on this, orking on, in fact, all nism and the communication , and we came very close proposal which tied lo tie together. The pation that is required, ess to an outside body -- it has to have this ype of minimal can carry if something on or proposal is t considered. Then the d use other arenas to media to get something proposal. Those things t, in my conception of

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DR. JONSEN: Participation makes sense if there is redress and grievance process. Otherwise it does not make much sense because you can cut it off at the roots.

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DR. IRWIN: In order to have a proper grievance mechanism you have to have two-way communication between some outside group who then tries to work the grievance mechanism by going to other sources of power.

DR. RYAN: John, you say you have been working on 9 this. Have you fleshed this out any more than it is on 10 page 80? 11

DR. IRWIN: Yes, no. I did not. I felt in kind 12 of a bind because on the one hand I am working so directly 13 in an effort to construct a plan in California which came 14 to nearly reach fruition in California during the month of 1.5 January which got tabled, got delayed, got put on the back 16 burner was the metaphor used by the Department of Corrections 17 because of some extreme hostility expressed by the 18 Correctional Officers' Association, but it was one that I 19 regret I did not bring. It is one that was worked up in a 20 long series of meetings between the Department of Corrections 21 and our group in an eight-month period, and it included the 22 right for inmate organizations inside to exist, to have an 23 outside affiliate and to regularly meet with the superintendent 24 and the higher echelon, if need be, and to aggrieve certain 25

specified things which were the rules of incarceration which 1 was the contract which we start with which was a very 2 rational and not a very outlandish proposal which the top 3 echelon of the California Department of Corrections helped 4 us construct. It was really one that was mutually agreeable -5 to both sides, but the lower echelon, the superintendents 6 and the guards found it intolerable, at least they do now, 7 but I would love to see that, and I did not bring a copy of 8 it, but I will certainly see that the Commission gets a 9 10 copy.

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I might be able to have one sent before tomorrow 11 on an airplane. 12 DR. RYAN: Are there other comments that anyone 13 wants to make now? We are winding down for the day. I can 14 see everyone with sort of a vacant stare and so on. 15 16 Don, are you going to wake us up? DR. SELDIN: Nothing very abrasive. On this 17 grievance and redress, whatever it is called, I think one 18 has to say something about its composition. I mean the 19 20 outside component that would lend it credibility. Now, I don't know just how to put this, but we ought to be sure that 21 say, newspapers have access to such a committee, that groups 22 which, in some meaningful sense are identifiable with the 23 interests of various prisoner populations are represented 24 on the committee so that the outside members of the committee ² 25

	ſ	21.6	and reserves						
	1	are not hollow. In other words, I think there ought to be	and the state of the						
	2	some specification that physicians on such an outside							
	3	grievance committee are disinterested in the way that Al	2						
	4	mentioned. They might be part of an institutional review	- 3						
	5	board of an affiliated university, something like that or a	4 4						
	6	medical school or a hospital, something like that. Newspapers	5						
	7	ought to be involved and perhaps groups like the American	6						
	8	Civil Liberties Union or the NAACP or something like that.	7						
	9	What I am trying to suggest is not so much these	8						
	10	particular organizations but a tone and a character to an	9						
	11	outside review board that would ensure that the interests of	10						
	12	the imprisoned are being met.							
	13	DR. RYAN: Are there other	12						
	14	DR. SELDIN: Nothing shattering.	13						
	15	DR. COUKE: I take it that the line of reason we	14						
	16	are developing is one way that might make it acceptable for	15						
	17	prisoners to be used?	16						
	18	DR. RYAN: Yes.	17						
	19	DR. COOKE: We are not excluding other ways of	18						
	20	making it acceptable?	19						
	21	DR. RYAN: Anything we have not talked about we	20						
dup	22	have not excluded yet, Bob.	21 >						
Bowers Reporting Company	23	DR. COOKE: For example, this might be an	Au 22 Borrens Reporting 24						
Reportin	24	alternative way to go, but there might be a way to go which	6 23						
BOWERS	25	is not to do the research in the prisons at all, do it	12 24						
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outside. You get your public exposure, et cetera. We are not saying that this excludes. It may be a way of doing it within the prisons, but there may be other ways of doing it. DR. RYAN: If you recall the letter, I tried to oversimplify the whole thing, but to sharpen it and to offer the two approaches which had been brought up before us, the one you just mentioned, the alternatives, plus the one that we are working on now, and it is my thought that perhaps some of us could try and pull some of these things together, that is the recommendations from the task force for the federal penal system, some of the staff suggestions, some of the things that have come out and try it out on us tomorrow, because the only way you are going to be able to check this is to say, now given this kind of a prison with these kinds of assurances and so on, now what are you going to do with respect only to biomedical research. Then we are going to have to tackle this with respect to certain aspects of the behavioral areas, and I just want you to start thinking about this.

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Miriam Kelty came to me and said, "You know, what are we going to do about rehabilitation, like work programs and early furlough programs, early discharge programs? Are they research. Are they therapy? Are they institutionalized in our society? What do you do when someone wants to validate them or compare one with the other?" And although everyone

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	1	219 that has come to us and talked about all of the things that	
	2		
	3	little that has been said or that has been written to us that	
	4	has recognized the fact that the only way you are going to	
	5	make improvements is by that mechanism, that bad word	An district and the second
	6	"research," and the thing is for society to have the wit	た。諸語に
	7	to do the right kind of research in the most humane fashion,	
	8	decent fashion, to redress some of these problems in the	
	9	prison system and society and so on.	
	10	So, we are going to have to think of some things.	
	11	We will try and bring something to the Commission tomorrow.	
	12	DR. STELLAR: As Pat just said to me in an	
	13	aside, if you separate out the behavioral section, we will	
	14	surely be here Sunday. Is there any possibility in the	
	15	interests of finishing in the two days rather than three	1
	16	days of taking your remarks into the behavioral area as well	1
	17	and trying to deal with both, at least in the same day?	
	18	I don't mean necessarily simultaneously.	1
	19	DR. RYAN: Every time we say anything that tries	18
		to conserve time for us, the whole United States is listening,	19
	20	and they are saying that this is so terribly important you	20
ž	21		21
Compor	22	should not damn the time, you know, take the time that	Auguro 22
, Gillio	23	is necessary. We will try tomorrow to do what we can.	£ ` ^ ^
BUWKIS KEDOUING COMPONY	24	Then we will send the Commission away to do a lot of	Bulliodaa 24
	25	reading, catch up on the reading and so on and so forth,	⁵³ 25
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while we are trying to draft the first result of the 1 deliberations. We will try the best we can to do both of 2 those, but I cannot be certain, but we don't want to slip 3 something in so that -- remember Pat was the one who said 4 to us, "Don't necessarily assume that what we accept for 5 biomedical we would for behavioral." 6 DR. SELDIN: What time tomorrow? 8 DR. RYAN: We are scheduled to begin at 9 o'clock. Get up early and read your --DR. SELDIN: I move we adjourn. DR. RYAN: We are adjourned. Thank you all. (Thereupon, at 5:04 p.m., a recess was taken until 9 a.m., the following day, March 13, 1976.)

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Saturday, March 13, 1976

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<u>P R O C E E D I N G S</u>

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DR. RYAN: I wonder if we could convene our meeting and move along. I would like to plan out for you, plan the day with you and see if you agree. I would like to break for coffee at 10:30 for only 10 minutes, to break at noon for lunch to be back in an hour-and-a-half, that is, 1:30 and go until 3:00 or 3:30 and then adjourn. If you can carry out this schedule, we will try and do it. I would like to devote the entire morning to a discussion of prison research.

10 The first thing in the afternoon, those other items that are on the agenda, the Quie letter, Congressman Quie, and 11 other things. We are not going to be able to take the kind 12 of time for some of those areas but I think it is terribly 13 important that we continue with the research discussion now. 14 If that is agreeable with you, we will proceed under those 15 general guidelines and you can make your plans. Hearing no 16 objections, I would like to call to your attention, then, a 17 double-spaced, single page, typed memo on your, at each of your 18 places, which is an outgrowth of some of the discussions that 19 Mr. Yesley, Steven Toulmin, John Irwin and I had last night, 20 trying to put together the concept of an accrediting mechanism 21

Inkeeping with that, we were not too specific but what we wanted to bring before you was how it might look and how certain controls might be put in place for those people who are cynical about the possibility that change can, in fact,

take place or that controls can be effective. And if I may, 2 I would just like to review it with you. The Commission recommends that the Secretary may conduct, support or approve and I think in that context one might be, refer to FDA activi-5 ties, biomedical or behavioral research involving prisoners 6 provided such prisoners are confined in a correctional insti-7 tution or facility and here, as far as I am concerned, it 8 doesn't have to be a correctional institution or facility. It 9 can be any facility that is regularly inspected, has been 10 certified by an appropriate review committee as conforming to 11 the following standards.

12 One standard is general conditions of inmate life 13 and John Irwin assures me that there are standards for that. 14 There are probably federal standards and guidelines that the 15 judge invoked when he said certain standards were not being met 16 in Alabama, for example. Two, an adequate range of opportunity 17 for employment, education, occupational training, leisure and 18 cultural activities and these could be defined. Three, compara-19 bility and level of remuneration for research and other employ+ 20 ment activities. We left out here renumeration vis-a-vis 21 activities in the outside world but I think that this, of 22 course, is subject to embellishment and change and what-have-23 you.

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standards which could be defined. I want to come back and talk 2 about that availability of accredited medical care in just a 3 minute. Regular access by prisoners to means of communication 4 with outside individuals and organizations according to the 5 guidelines, for instance, that Al Jonsen was talking about yes-6 terday, that is, provisions for uncensored mail, for access to 7 telephones. Now, these are conditions for all prisoners in 8 an institution and are not concerned merely with the conditions 9 existing for people undergoing research.

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10 In other words, the facility itself has to meet these 11 standards so that the society within the prison can sufficiently 12 control their own destiny, that one could entertain the possi-13 bility that research could ethically go on. Regular access to 14 prison by outside individuals and organizations, including 15 media and advocacy groups, and this could be spelled out. 16 Opportunity for prisoners to organize, to subject grievances 17 to arbitration and to participate in decision-making regarding 18 the conduct of research in prison. This goes to the suggestion 19 in the staff paper regarding the provisions referrable to be-20 havioral research. Many people said behaviora research could 21 be acceptable if the prisoners themselves said they wanted it, 22 if they retained theright to refuse and if they had some par-23 ticipation in setting it up.

24 It seems to me that some of the programs that Dr. a 25 Brady described that were not, in fact, research projects

involved prisoner organization run participation peer pressure. Provided further that each protocol covering such research has 2 been approved by a review board, the members of which include prisoners, and if you want prison advocacy groups, in and out of the prison, is accompanied by evidence that the correctional institution or facility has been inspected and certified accord-6 ing to the standards above within some specified time. Here 7 8 we just said six months.

9 Now, I want to say a word or two about the one area of health care and then I will throw it open for discussion. 10 11 I just happened to be talking to a classmate of mine, who is concerned about such things as chronic disease and hypertension 12 and had entertained the thought of trying to do studies in 13 prisons and so on and so forth. And I asked myself, in relation-14 15 ship to this, what legitimacy does the federal government have 16 busying itself with biomedical and behavioral research if it doesn't busy itself first with the health care, both mental and 17 18 physical, of men in prisons. And I think for the federal 19 government to start setting rules and regulations or to in-20 fluence city, county and state jurisdictions in prisons, the 21 federal government should have the same kinds of concerns for 22 the health care of the these prisoners. 23 There is a mechanism via Medicaid and via other 24 kinds of grants that if the federal government did set up this a 25 kind of program, that could ultimately come to the good of

1 society, not only from biomedical research which is generated 2 but the concept of federal government being concerned for the 3 health of prisoners within prisons themselves. This is just a 4 halting step, I think, in that direction but it does provide 5 a legitimate role for the federal government with respect to 6 drug testing and so on.

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But I think only insofar as the federal government 7 equally assumes responsibility for the health care, the way that federal judge said conditions in this prison are so poor 9 that I am going to take them over and take them out of the 10 jurisdiction of the state. I think there is an opportunity to 11 do something small for the Commission, not too grandiose but 12 perhaps creative, in this particular area. With respect to 13 the question of chronic diseases, this physicians indicated to 14 me, for instance, the concerns about hypertension, seeing what 15 happens in hypertension, the opportunity to provide therapy for 16 such people at a similar time or a standard of health care. 17

So, I would say the federal government really is just scartching the tip of an iceberg if it says to this Commission, hey, worry about research on prisoners but it doesn't really say, hey, worry about the health care of prisoners. And I would like to stress that. But this document, as a starting point for the Commission's deliberations is offered to you and I would invite discussion and comment.

DR. JONSEN: I move that statement.

DR. BRADY: I have two things that I would like to add here --3 DR. RYAN: Why don't you just second? We don't have to vote on it. We will open it for discussion. 5 DR. BRADY: Okay. Moved and seconded. 6 DR. RYAN: Now we can discuss it for the rest of the 7 day or some other day. 8 DR. BRADY: Yes. Well, I think this has the frame-9 work of a -- there are two things I see here that I just put 10 in in red. Item No. 3, which has to do with comparability and 11 level of remuneration for research and other activities. 12 Nothing in here speaks to the comparability of opportunities 13 for other employment activities, which I think is --14 DR. RYAN: That was supposed to be under 2, it is 15 perhaps not well-enough stated. 16 DR. BRADY: Oh, okay. I would just add comparability 17 between the opportunities for and in the level of remuneration 18 for research and other employment activities. Down in No. 7, 19 the critical feature there which has to do with the opportunities 20 for the prisoners to organize, subject to grievances and prin-21 cipally to participate in decision-making, not only regarding 22 the conduct of research in the prison but the objectives and 23 the conduct of research in the prison. I think that is one 24 of the major concerns, not only how it is done but to what end 25 They should be able to participate in what it is about to the

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	1	extent that it is in their benefit, they ought to be able to	a i sugar	
	2	DR. STELLAR: Would you want us to amend that and		care. It is ambiguous here as
	3	say objectives of behavioral research?	2	I think that if one s
	4	DR. BRADY: No, they ought the objectives of even	3	tional arrangements in the pris
	5	biomedical research ought to be consummate with what the		for these arrangements and spec
	6	prisoners want. If they cannot agree with the objectives of	5	listed here, including such thi
	7	the program, regardless of what the research program is, then	6	so on. Then the second categor
	8	I don't think they should be required to participate.	7	for biomedical and behavioral r
	9	DR. RYAN: Dr. Şeldin.	8	this category there are several
	10	DR. SELDIN: First of all, I think the people who	9	to be spelled out more in detai
	11	drew this up ought to get some credit for having prepared such	10	I feel, is some sort of regular
	12	an excellent working paper in so short a time. I think it	11	of the things mentioned here, p
	13	would be helpful to structure these standards in terms of	12	DR. RYAN: You don't
	14	standards for the prison in general and standards for biomedical	13	committee?
	15	research in particular, some such phrase as conforming to the	14	DR. SELDIN: Yes. I
	16	following standards with respect to the institutional arrange-	15	That could be done by some of t
	17	ments in the prison in general and of biomedical and behavioral	16	mentioned and, again, I think t
	18	research in particular. Then categorize the recommendations	17	spelled out. In other words, a
	19	in these two dimensions so as to make crystal clear we are	18	protocols. You have got that h
	20	talking about the prison setting on the one hand, certain	19	another kind of body where the
	21	minimum standards. For example, I think that in view of some	20	members of the community are re
Aux	22	of the remarks we heard, it would be very important to ascertar	21	members of the community. You
d Com	23	that there was adequate medical facilities in the prison in-	22 000	Advocacy groups, that is fine.
Reporting	24	dependent of the research project, so that this doesn't become	outroot	it, as well as physicians, dis:
BOW2IS	25	a subtle kind of coercion, to have access to better medical	a 24	of arrangements at the Univer
			°≊ 25	as being very sound, so that the

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it now stands.

set forth a category, instituson, certain minimum standards cify many of the things that are ings as biomedical research and ory would have to do with standard research in prison. Now, under 1 things that, to my mind, ought il and the most important thing, arly seated committee consisting prison members themselves --

mean an IRB now, you mean another

I am not talking about review. the mechanisms that Al Jonsen that should be specifically a review body to scrutinize here but I am talking about e prisoners are represented, where represented, I mean realistic u have mentioned that here. . That is a good way to mention sinterested physicians, the sort ersity of California strike me there can be no question that the

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	3	openness is not compromised by the warden or the prison groups		1	had that in mind. On the other h
	2	or the jailers, as has been termed, constituting a coercive			are going to do, if you are not g
	3	group which cannot be circumvented because there is no access			in research activities down to th
	4	outside.			in the prison yard and working in
	5	Well, that would be the major thing that I want to			factory, et cetera, then it becom
	6	suggest, that the body be specified that performs this function			are talking about. Are you tryin
	7	in the section having to do with biomedical and behavior		7	
	8	research in particular.		8	what is being paid in terms of pa
	9	DR. RYAN: Pat King.			vities?
	10	MS. KING: I would like to congratulate everybody		10	Which brings me to anot
	11	that worked on the document but I think that the document as		11	not regulated by the state and it
	12	it is, and I have specific criticisms, points out my own per-			terms of how you devise a payment
	13	sonal dilemma, I think, even more so and that is that the			does one set that standard for pa
	14	meanings of the words which probably cannot be defined in any			or what had the drafters in mind
	15	greater specificity are still such that I am not satisfied.		15	DR. RYAN: Let me start
	16	I don't know what "adequate" means. Now, if I ran the world,		16	proprietary interest in this
	17	if I ran HEW and set up the final system, I might feel better		17	MS. KING: I understand
	18	about it, but I don't. So, I have difficulty with it, and I		18	DR. RYAN: It is a crea
	19	understand some of the limitations, in trying to be more		19	you would help us more, Pat, by s
	20	specific.		20	it is not adequate enough. You m
	21	I have a specific problem with No. 3, about compara-		21	look, I think that the remunerati
npany	22	bility and levels of remuneration for research and other employ	Jupd	22	or define it, comparable to what
Bowers Reporting Company	23	ment activities. I have several problems. One, the way it is	∦ U.		world, that, in fact, slave labor
s Report	24	written that could mean you could pay for research the same	Reportir	24	MS. KING: The Federal
BOWEL	25	thing you paid for license plate making and I didn' think you	Bowers	25	adopted a comparability level in t
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hand, if that is not what you going to bring participation he payment levels for working h the factory, in the shoe

nes a question of what you ng to talk about raising the te factory up to the level of articipation in research acti-

ther question, that if it is may very well be already, in system, if it isn't, then how ay and what had you in mind, when they wrote this? tout by saying no one has any

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ation of the Commission's and saying I don't like that because hight help us more by saying,

ion ought to be somewhat comparable is going on in the outside shouldn't exist.

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Bureau of Prisons report

task force's recommendations, with what is being paid in the outside world.

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DR. RYAN: Okay.

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MS. KING: That would be the level, I think, that should be used and I only raised that because it seems to me 6 that that creates enormous problems in terms of bringing up the other pay scales in a prison. You are into the situation, I think, that John Irwin stressed yesterday. I am not sure I agree with him, but that would certainly put us in the situa-10 tion of making it so impossible that states may really consider not funding or not allowing research in prisons because of the 12 problems of bringing up the pay scales for other activities. 13 DR. RYAN: Bob Cooke.

14 DR. COOKE: Well, as usual, I am going to sound a 15 negative note. Let me give you my reaction which is not against 16 the -- I can see what you are attempting to do, all right. But 17 I find this a little bit offensive. I find it a kind of des-18 cription that the Department of Agriculture might possibly put 19 out in terms of the housing and caging of animals. And I get 20 the feeling that we are talking about a group of slightly sub-21 human individuals that if we frame things adequately enough, 22 it is okay to work on this group, and I can see why the Euro-23 peans, maybe, have not taken to prisoner research because 24 this seems to me to make them a kind of special group of a 25 people, non-people, where if you do enough things, have the

caging and the housing and the feeding and all that right, then it is okay to work on these people. 3 I think you have got to go farther than this, it seems to me. I think you have got to show the comparability of -5 these persons to other people in the free world and I think the only way you are going to have that occur is when you have free world people participating in the same protocols. I think that is the real sign of choice going on. Otherwise, I think this is a lot of maneuvering to sort of be sure that the 10 environment is nice and the air is fresh and so forth, and I am not satisfied with it.

12 DR. RYAN: Your suggestion is an add-on? You want us 13 to throw this out? Or you want us to just say --14 DR. COOKE: I don't know. I think that this may be 15 a nice way to make the prisons better but I am not sure it 16 really does say that prisoners are like other human beings in 17 regard to research activities. The way they are like other 18 individuals is to have them participating the way other indi-19 viduals do and have other individuals participating with them. 20 DR. RYAN: That is not exclusive. 21 DR. COOKE: Not necessarily exclusive but I feel 22 that until you add that other element it sounds like the 23 Department of Agriculture to me. 24 DR. RYAN: Okay. You have that on page 80 of the ² 25 staff report, that is, concordance. You can participate in

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	1	research if non-prisoners are also included or non-prisoner		
	2	projects are comparable or research is suitable for non-prisoner	s 1	take and there are, in fact,
	3	as well as prisoners. I sort of accepted that as a given, but	2	if I can refer to the Univers
	4	you feel that it has to be made quite explicit?	3	people who do the most prison
	5	DR. COOKE: There is absolutely nothing here that	4	lities and offer their protoc
	6	suggests	5	they have done. So the same
	7	DR. RYAN: This is not meant to be inclusive but I	6	prison are offered to the out
	8	think that you have identified it as something	7	there is a similar situation
	9	DR, COOKE: I am coming down to the protocols now.	8	DR. COOKE: They wo
	10	This is a general description of the prison environment, out	9	in the free world, too,really
	11	of which these people come. But now I am trying to say there	10	DR. JONSEN: Well,
	12	ought to be conditions imposed in regard to these particular	11	tance rate is in either of the
	13	protocols that assure that these individuals are not guinea	12	am trying to say is that basic
	14	pigs, animals, subhuman, et cetera, and the best assurance there	13	and doesn't really go to the
	15	is that other people participate.	14	being offered the same risks a
	16	DR. RYAN: Dr. Jonsen.	15	the prison conditions. It see
	17	DR. JONSEN: I would like to make three comments.	16	to do is to, to use the term
	18	Two of them have to do with what Bob just said. The idea of	17	the inner conditions as close
	19	free living people being involved in the same experiments or	18	state outside, so that with re
	20	being offered the same experiments has some interesting advan-	-19	living there is comparability
	21	tages to it. I think they largely pertain to risk-taking more	20	So, your concept is
Company	22	than to anything else. They still don't answer the question	21	actual test to say would peop
ng Con	23	of what, in fact, happens to people who are behind the walls.	Company Company	the same risks. But you stil
s Reporti	24	All it really tells you is that free living people are willing	orting C	an approximation to the free
Bowers	25	to take the same risks that somebody inside would be willi ^{ng to}	24 52	society. I would like to suge
			² 25	this might be along the lines

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examples of that. Once again, sity of California, we did ask n work to establish similar facicols to their out-patients, which protocols that are done in the c-patients. That is the same thing at Jessup.

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ould have to be accepted by people , not just offered.

I cannot tell you what the accepnose two institutions but all I ically the question is of risk issue of what happens when people are inside the prison and with eems to me what this is an attempt I have used before, to approximate sely as possible to the free living regard to a number of modes of

s valuable insofar as you have an ole in the free living state accept I have the problem of creating living state within the closed ggest that one nice addition to s of our, in our fetal research

234 recommendations. We included some deliberations showing the 2 rationale and a prelude to this, or prologue, might make it 2 3 clear that this is not the care and feeding of animals, that 3 it is precisely an attempt to state that the environment of 5 the prison should be one in which the maximum possible free 6 interchange of information and choice is made -- that is the 6 7 condition we are attempting to create. We are not just trying 8 to keep clean cages. 8 9 Just a final, third point. Would it be advisable 9 10 to include in these recommendations a recommendation that there 10 11 be a national body appointed to oversee the accreditation pro-11 12 cess or do we want to leave it to the Department to do it with-12 13 in its ordinary inner workings? Should we ask for an outside, 13 14 public advisory body? 14 15 DR. RYAN: I think that is an issue --15 16 DR. JONSEN: Accreditation body. 16 17 DR. RYAN: That is an issue that we were uncertain 17 18 about and would be a moot point unless the concept was valid 18 19 as far as the Commission is concerned. I hope we can get off 19 20 the slang expressions about prison life, although I think that 20 21 the very descriptive nature of the use of words, "cages," and 21 22 so on and so forth, points up the simple fact that although 22 23 that is shocking to people when they perceive it in that way, 23 凝 24 that is the way the real world is and I suppose if we do 2 24 ā 25 anything to change it a little bit, it might be worthwhile. ² 25

Dr. Stellar. DR. STELLAR: Al covered most of what I wanted to say and did it very well. The only additional point I would make in response to Bob's parallel to animal care is the decision-making process which these people are participating in. This seems to me that that alters the situation very greatly. I think it is a caricature to make this an animal care, Department of Agriculture situation. DR. COOKE: You know, I don't agree with you, Al. If you read those essays on the prison culture, I don't think you are going to affect the prison culture one bit by all this. I really don't. You have got a culture there that I think makes it very difficult for individuals to choose freely. It is quite different from the free world and no matter what you do in regard to these procedures, I think that kind of culture is still going to be there and is going to be a kind of oppressive effect and therefore, it seems to me, we have to do something in addition. Now, as I looked at these there was very little that. seemed to be in there that would have kept people from participating in protocols that I think would be unacceptable to people in the free world. That is why I think we have got to

> DR. STELLAR: I agree with that. DR. COOKE: It is largely in the risk area that we

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are talking about, but I think we need that additional protection.

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3 DR. STELLAR: That was part of my agreement with A1. I agree with that, the additional protection, but I just wanted to add this other view. I think we won't change the culture 6 but I think for those subjects, prisoners that are involved in research, I think we put it on another level if it works. 8 DR. RYAN: Stephen, please.

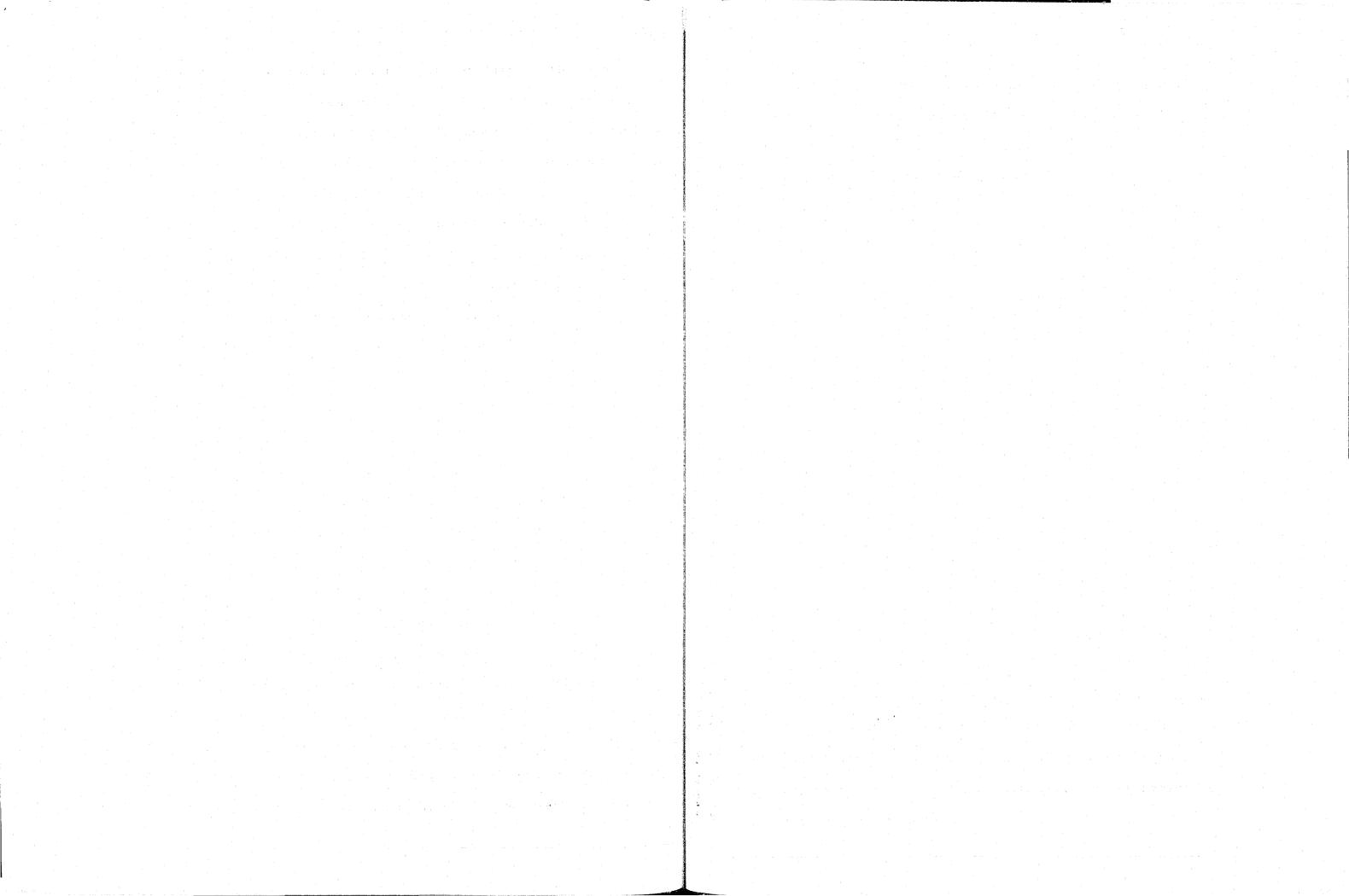
9 DR. TOULMIN: I, think John Irwin can speak to a lot 10 of these questions much better than any of the rest of us and 11 I think he will when he gets here. I mean here in our dis-12 cussions last night it was quite clear that item No. 7 was 13 an item which, if it works, would be capable of modifying the 14 conditions that Bob Cooke was just speaking of; if, indeed, it 15 were possible for prisoners to organize and subject their 16 grievances to arbitration effectively and to participate in 17 a lot of the relevant decision-making that this would make a 18 substantial difference to that decision and take them out of 19 the category of being caged animals and put into much more the 20 category of rational beings who have some control over the 21 relevant aspects of their fate.

22 I am sure John can say much more than the rest of us 23 can from his experience in dealing with the California prison 24 authorities over the last period of time, just how this kind 25 of thing should be cashed in in detail if it is going to have

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any chance of being effective. But I just want to say that No. 1 2 7, as we framed it, was directed precisely at the point that 3 Bob has raised and if we can re-word it in such a way as to 4 put his anxieties at rest, fine. 5 DR. RYAN: I am sorry, Karen Lebacgz. 6 DR. LEBACQZ: Like Al, I am operating on the assump-7 tion or the hope that any such statement of recommendations will be preceded by a statement of deliberations and conclu-8 9 sions and would want to reiterate his concern that that should spell out the rationale. I would also like to see that state-10 ment include your concern, Ken, that we make a very strong 11 statement to the effect that concern about research in prison 12 must be seen in the light of a larger concern about the adequacy 13 14 of medical care in prison. That seems to me very important. 15 Then I had a couple of very specific comments here. 16 I share Pat's concern on the issue of remuneration. I am very 17 troubled by that. It sounds right now as though we might end 18 up saying that the federal government or the drug companies or 19 who else gets a nice, cheap market --20 DR. RYAN: We should re-word that. 21 DR. LEBACQZ: And I am not sure that is what we want 22 to do. 23 DR. RYAN: Or tell us what you want. 2 24 DR. LEBACQZ: Well, I haven't figured out how to re-

25 word it yet but it seems very clear to me that what we want is



The real thing that we have to confront, and the hardest and therefore, I think, the most immediately important, 2 concerns No. 3 on comparability and level of remuneration. 3 There, I think, the nail has already been hit on the head by 4 the comments made and that is that there must be equivalence of -5 compensation within and without the prison. 6

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Now, admittedly, we are then catapulted into a 7 terribly difficult area because by raising the rate of compen-8 sation of prisoners for research to that which would be accord-9 ed students or anybody else in the outside, we, of course, 10 directly involve the situation within the prison. In other 11 words, a substantial rate of compensation for the research in 12 juxtaposition to a very low rate of compensation for other 13 industries within the prison, this is the hardest of all the 14 problems. The other problems, the postponement of arbitration 15 until there has been a due grievance proceeding within and so 16 forth, they are all very solvable, very standard, reasonable 17 18 approaches.

But this is the ultimately difficult thing and this 19 may be the thing that will produce in our standards an im-20 possible norm in relation to the realities of a modern indus-21 trial society. But how can we give to the prisoner the rate 22 of compensation that goes to the outsider for research? And 23 admittedly, there might be some equitable adjustment here; for 24 example, a compensatory payment by the prisoner to the state a 25

for a reasonable apportionment of his maintenance and so forth 2 but even so, it is going to be a significant change and then 3 are we also in a position to pull up the other industries with-4 in the prison? This, to me, this is the ultimate difficulty 5 that we have got to face and if we can solve this in some both 6 theoretically sound and feasible way, I can almost guarantee 7 the other things, including the method of describing that these 8 are human beings we are talking about and not just Department 9 of Agriculture concerns.

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10 Those can all be met, I think. But this one, I must 11 admit, defies me at the moment for a rational solution. 12 DR. RYAN: Joe.

13 DR. BRADY: I think, there seems to me to be an impor-14 tant distinction that we should keep in mind. Indeed, in fact, 15 we are striving very hard to assure that we don't overlook the 16 | fact that we are dealing here with human beings but it is also 17 unrealistic to assume that the status of these human beings is 18 different from the status of other human beings who may be 19 involved in the same kind of a situation and largely by virtue 20 of their own performances in the past. 21 this doesn't represent to me an impossible Now, 22 situation simply because while you can argue to the requirement for comparable levels of compensation, it seems to me not 23 1 24 essential that the compensation accrue directly to the indivi-\$ 25 dual. That here is an opportunity, for example, if this is

242 handled properly, to get another feature into this situation Ŧ so that the social benefits of the prisoners' participation 2 accrue not to the society in general alone, but to the particu-3 lar society of which he is a part and here is his opportunity 4 to contribute in that respect. So, that he doesn't necessarily 5 get \$27.00 an hour but perhaps the institution and the com-6 munity of which he is a part profits from that level of compen-7 sation in some way and that is an additional contribution which 8 he makes to his own community, to the limited different com-9 munity than the one --10 DR. RYAN: Joe, that is what Karen was referring to 11 and it is in here and that is that sufficient money go into 12 the prison so that the prisoners are given amounts of money 13 that are comparable, reasonably comparable activities, that 14 the overage, then, be given to the prison to benefit the 15 prisoners. 16 DR. BRADY: These are not absolutes we are talking 17 about, but while, as John pointed out yesterday, what you are 18 dealing with here is a system which is constantly in flux, 19

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more so now than it ever has been before and as the -- what we 20 are talking about, really, is for protionality or comensurabi-21 lity. As the standards improve in the general population, 22 then that adjustment is made within the research system as 23 well. So, I don't see that as an impossible problem. 24 DR. LOUISELL: Not impossible, but very difficult. 25

DR. RYAN: Pat King. 2 MS. KING: Well, I wasn't going to talk about what 3 David and Joe were talking about but I would like to make a 4 preliminary comment about that and that is, I don't trust things 5 | that says the excess has to go to a prisoner fund or return to prisons. Our experience and history of prisons is you run 7 into all sorts of problems with prison funds, who controls them, disappearing money, a whole bunch of things that I won't 9 get into.

10 It seems to me if you have to talk in those veins, you are talking about one of two things. The prisoner, all .11 prisoners, as a result of being incarcerated, must be asked to 12 work or must work as long as they are physically able, includ-13 ing participation in research, to help defray the costs of 14 their incarceration. That is a totally different kind of penal 15 model than we have ever had before and if we had that kind of 16 model, then it seems to me that the proposals for pay and where 17 they went would make a little bit of sense. We don't have that 18 .19 kind of model.

I distrust asking somebody to work in an area and 20 then say, if you don't make everybody do it, we are going to return a portion of this or some measure over and beyond to 22 some environment -- it doesn't have to be a prison fund, it 23 can go back to the state. I just don't, I have real difficulty with that. I think it should go to the prisoner for his \$ 25

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	1	family, for when he gets out and can, perhaps, get a start back	1	perhaps that goes back to Don's idea
	2	in the world or help with his rehabilitation. We are talking	2	at the research protocol and then at
	3	about an entirely different concept, but that is an aside.	3	those two would go to who can actuall
	4	What I really wanted to suggest was some additions	4	research.
	5	to the sheet of paper that came from the Federal Bureau of	5	DR, RYAN: Dr. Cooke.
	6	Prisons. There are two points that I thought were very good.	6	DR. COOKE: I think David h
	7	One was that prisoners must be compensated for all lasting	7	compensation issue is certainly one c
	8	injury or loss of earning suffered as a result of participation	8	todeal with here in this particular s
	9	in their research projects. We have not discussed the issue of	9	have equity there, you obviously will
	10	compensation in general but I think that any system, anything	10	at least, of a sizable degree in rela
	11	we propose should have that as a recommendation.	11	in the prisons. And certainly I have
	12	Two, I liked their proposal No. 1, that the indivi-	12	rest of the prison wage scale is goir
	13	duals who were to serve as subjects this one I am proposing	13	I must say my agricultural rules here
	14	tentatively, unless I hear something that could possibly im-	14	sound a little more agricultural wher
	15	pact on this who serve as subjects volunteer from a pool of	15	ment of the funds is very difficult t
	16		16	to supervise the ambience of the inst
	17	modification. I am debating, I think that it might be worthy		pessimistic about all this.
	18	for the Commission to face the Federal Bureau of Prisons' pro-	- 1 <u>4</u>	What I would like to say sp
	19	posals that the prisoners who volunteer must come from a less	19	compensation and I would hope it woul
	20	restrictive environment than the one which they are going to.	20	and not simply applicable to the pris
	21	They suggested that the volunteers should come from camps and	21	to somewhere, when we talk about comp
mpany	22	kind of trusty-type positions. I think that is worthy of	122 L	compensation is unrelated to risk and
Reporting Company	23	debate. I can see problems with it on both sides.	ຍ ຊ_23	to time and inconvenience, possibly.
ers Repo	24		24 24	Berkeley proposal at one time that wa
BOWERS	25	that we might want to discuss a little bit about the pool and	25	courts, in which there were differend
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of looking at some point the prison too, and perhaps ly participate in the

has made a point that the of the most difficult ones situation because if you 1 have a bribery component, ationship to other payment e no confidence that the ng to be raised that much. e, which I referred to, n Pat says even the manageto supervise, and you want titution, so I am a little

pecifically about the ald be a general statement soners. I think we have apensation, make sure that ad that it is related only

It seems to me that the as, I believe, in the ces in hazard to the

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	1	children and greater compensation, as I recall, if there was	ા . આવેલાં કરે છે. તે લેવે શાળ		
	2	more hazard, obviously is really very undesirable feature.	n o si chu cu cu		know, it is important to include pris
	3	So, I would think we ought to build in a level, some kind of	and and the second second second		what we are reading about, the review
	4	guidelines, in regard to compensation that simply make it in	nter a treatment data (1947)	3	to be, you know, really bureaucratic
	5	terms of time and even the inconvenience issue I find a little	Analysi Shek - Cak	4	me that it is very important if we co
	6	hard to quantitate. But certainly not related to risk.	and a state of the second	5	the review board whose members are
	7	DR. BRADY: A service contract, rather than a product.	- The part of the second second	6	racially and ethnically representativ
	8	DR. RYAN: Mike has a question about clarification,	n an 1944, status	7	to the prison population. I think th
			u ja un dreisen a Bleg	8	whole system and, also, to prisoners.
	9	please.	รดาว ให้สมเขาเป็นเขายะว	9	that is a very constructive(?) thing
	10	MR. YESLEY: Could I just make a suggestion that for		10	whereas we may later somewhere discus
	11	choice of words, you use "compensation" to mean taking care of	And a third a formed of the	11	like to see it still here.
	12	a person who has been injured and "remuneration" for	n to a Children of the series	12	DR. RYAN: Dr. Seldin.
	13	DR. COOKE: Okay, remuneration. Remuneration un-	ar Generative Joseff da	13	DR. SELDIN: I want to make
	14	related to risk.	S 10 ¹ Factority of State	14	of compensation and then a general co
	15	DR. RYAN: Dorothy Height and then Dr. Seldin.		15	tion goes, there seem to be three sta
	16	MS. HEIGHT: I think I agree with some of what Pat	2	16	remuneration is being discussed. On
	17	was just saying, but it seemed to me that those were conditions	an a	17	that the drug companies should not, i
	18	that affect the research and maybe, I felt that this statement	an for all and the line of the	18	cheap, exploitable human subjects on
	19	the strength in it, was that it was dealing with the thing	a the formation of the form	19	in this sense, then, one is saying th
	20	that we have heard so much, which is that the prison is not a	nate of the Charles of the Charles	20	ought to spend a fair amount of money
	21	place where one can make a decision without a sense of un-	an an Sin an Anna an Anna Anna Anna Anna Anna A	21	not exploit the posture of a prisoner
Company	22	coerced free will. Therefore, it seemed to me, that the	Jupc	22	labor, so to speak. That is one star
ina Cor	23	strength in this is that is addressed to the prison as the	Com	23	what the drug companies are paying.
Bowers Reporting	24	prison. And in that regard, I look at the last part of 7,	Dortic	24	A second would be what rest
Bowers	25	where we refer to the review board, and I certainly you	SI2M	25	on the outside as compared with the
			- States and the second		

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include prisoners -- but considering
, the review boards and their tendency
ureaucratic bureaucratic, it seems to
ant if we could say something like
mbers are -- I would like it to say
epresentative, has some relationship
I think this is a vital lack in our
prisoners. But it seems to me that
.ve(?) thing to have right there,
ewhere discuss review boards, I would

want to make a comment on this matter a general comment. So far as remunerabe three standards in terms of which scussed. On the one hand, one states should not, in a certain sense, have subjects on which to do research and is saying that the drug companies ount of money to get it. They should of a prisoner in order to get cheap t is one standard of remuneration,

be what research subjects are getting ed with the inside. And a third would

be the general level of remuneration within the prisons for other kinds of activities. Now, I take 3 to refer to the 2 third. That is, it doesn't make a statement regarding drug 3 companies and it doesn't make a statement regarding comparability to comparable wages outside the prison. This statement 3 5 seems to me unambiguous. Other employment activities within 6 the prison I take this to mean. 7

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Now, I feel that that is a very, very important point, that the level of wages set within the prison should consti-9 tute, as Dr. Cooke mentioned, a kind of oblique bribery where 10 one is setting the wages so high that, in effect, one is making 11 research tremendously attractive thing for sort of illegitimate 12 reasons. So, I want to endorse the three just as it specified, 13 perhaps adding "and other employment activities or opportuni-14 ties within the prison" to emphasize the fact that one is talk 15 ing simply about what you get, let us say -- what did you say? 16 For making license plates or whatever other wage structure 17 there exists within the prison. Research activities shouldn't 18 be drastically out of line. 19

Now, a second point I want to make concerns issues of 20 adjustment and scrutiny. It seems to me that once again there 21 ought to be ways to change things that are built into it, that 22 things don't become frozen and rigid. It is possible that a 23 wage rate is ridiculous and that is not catastrophic if it can 24 be changed after a reasonable amount of time. It is possible 25

that certain activities, no matter how well-intentioned, get 2 calcified and there ought to be ways to change that. Now, 3 ways to change it constitutes, to my mind, anyway, a call for 4 two different devices.

5 One is some statement about institutional review 6 boards. These are more specifically narrowed to the conduct 7 of the research project, emphasizing what institutional review 8 boards always emphasize. But on the other hand, it seems to me 9 that there ought to be a second one constituted on prisoners, 10 maybe of ethnic and racial representatives, but also public 11 representatives who, in some sense, scrutinize this sort of 12 activity and are able to make judgments about it and who meet 13 at specified intervals so that it is not just when they are 14 called into being by some catastrophe that besets. In other 15 words, they scrutinize and oversee that these activities, both with 16 respect to the prison in general and the research in particulat, 17 are proceeding as the protocols specifies they proceed. 18 Now, it says here, has been inspected and certified 19 within the preceding six months. But it is hard to get the 20 sense that there is continuous review. What I am trying to 21 suggest is that two boards be set up and --22 DR. TOULMIN: Can I speak directly to Don Seldin's 23 point? Very quickly? 24 DR. RYAN: Yes, you may. a 25

DR. TOULMIN: I do think the document as it stands

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is unclear, that we are referring to two committees and, indeed, 2 that maybe there ought to be three committees. Let us, as a З group, simply remove that unclarity in the document. I mean, 4 it is clear that there is going to be some overall review 5 committee or set of regional committees which, under the authori-6 ty of HEW, would have the task of certifying that prisons meet 7 these standards. 8 But within the prison there is going to be an IRB 9 which would have the normal functions as an IRB but my own 10 feeling is with you, that there should be a different committee 11 which has the task of overseeing the relationship between the 12 entire research activity and the rest of the prison and that 13 this is the one that you wish to have added to the document. 14 DR. SELDIN: Yes, I think it should be spelled out. 15 DR. TOULMIN: I think this is good. 16 DR. SELDIN: And it addresses to your question, Bob,

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17 too, to make certain that the overall civilization of the pri-18 son vis-a-vis not only the research program but its balance 19 with the rest, be reasonably dignified.

20 DR. RYAN: I am going to call on Bob Levine and then 21 on John Irwin, but before John Irwin speaks, I want to ask him 22 some specific questions to respond to. But, Bob, start.

23 DR. LEVINE: On the issue of setting up dual com-24 mittees within the prison, some of the functions that Don a 25 Seldin has specified for this second committee, I think, are

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represented on the IRB. Some of the things I was asked to put together on what the ordinary IRB looks like and what it does 2 do include quite a number of these functions and I do think 3 that it is quite possible to build the ethnic, racial and 4 5 public representation into the IRB so that the sorts of considerations that one would want to address through such represen-6 tation could be accomplished in the context of the IRB meeting. 7 8 I think that, as you were talking, Don, you were talking about how some sort of structures tend to become cal-9 cified and go on doing their thing, possibly in a duplicative 10 11 way, and possibly in an unnecessary way, might be accomplished 12 unless we could really find out what a second committee, the 13 establishment of a second committee within an institution, 14 could accomplish that couldn't be accomplished by the first. 15 As I understood it, the way this draft was written, the other review structure or committee would be outside the 16 prison, would have much more to do with matters of accredita-17 18 tion and some of the other things that might be coordinated 19 between institutions. I do wish we might consider the IRB and 20 how it functions generally before we consider novel variants 21 of this to apply to separate institutions --22 DR. RYAN: I think we will have to elaborate that. 23 Part of the confusion there, Bob, is that the three committees 24 or agencies, one to accredit, which has to be outside the ² 25 prison, one to be composed of prisoners in the determination of

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their own activities with respect to general prison activities and, third, the IRB related to research. Then one could define those three. The third committee, the other prison internal committee, would be concerned with general prison life to be sure that there was a mechanism for prisoners to organize, to qet grievances' arbitration, participate in decision-making regarding objectives and conduct of research and other prison activities has been added now.

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9 Now, John, before you start, one of the areas which 10 has been of most concern to the Commission members, enunciated 11 just before you came, was the question of compensation --12 remuneration, excuse me -- remuneration as it relates to the 13 outside world. I think everyone feels that you shouldn't be 14 given more for research than other things which could be 15 construed as a kind of inducement or bribery, but what about 16 the question of the fair return for the prisoner for his acti-17 vities while in prison. Pat King's concern that any kind of 18 prison funds could, like a union fund, for example, could be 19 subject to misuse.

I think in that respect prisons probably don't differ from the outside world. So, the question of putting it in trust or going to the prisoner's family and since you have been talking to prison officials, what sort of an economic problem is it to not use prisoners as, I use the word in quotes, slave labor or indentured individuals. To what extent can prisoners

find gainful activity or prisons find gainful activity for their prisoners and remunerate them in the society for that? And how would we handle the funds? This, David Louisell says this is a major problem. Can you give us some enlightenment? 5 DR. IRWIN: Well, he is right. It is a sticky legal problem. There are all kinds of legal barriers, there are all kinds of administrative policies which get in the way of any fair distribution of inmate funds. There are all kinds of inmate funds. There is usually, in most prisons, an inmate wel-10 fare fund which gets fed into by a variety of sources such as 11 when prisoners sell something from a hobby shop, 10 percent of 12 the sale goes into the inmate welfare fund. So, it is called 13 the inmate welfare fund but it is not in the hands of the in-14 mates. It is fed at the discretion of the department and 15 sometimes it is fed in very strange ways. It is fed to pay 16 staff members wages, and so on. 17 In California we have a couple of suits that are 18 still in operation on the inmate welfare fund, the misuse of 19 it. There is another complicating, new development in the 20 courts. In Soledad they set up a school program for veterans 21 who have, it was determined by a Veterans Administration deci-22 sion that they were going to full-time college which became 23 possible with an attachment to the local community college, 24 and they could receive full veterans' benefits which was ² 25 something like \$270.00 a month, which piled up very quickly in

prison. So they decided to, instead of lodging it in the 2 regular location for inmate funds which the State then draws 3 interest on but does not turn it over to the prisoners, they 4 negotiated with an outside bank and deposited their money in 5 an outside bank and the Department of Corrections went to the 6 bank and threatened them and forced them to return the money -7 to the normal prison funds. But this is being litigated. 8 So, it is a very, very sticky issue. I don't think 9 it is insolvable. I think the solution is to, just for the 10 Commission to, in a document like this to have some statement 11 that there should be the establishment of a general fund which 12 would come out of the difference between what is paid a prisoner 13 subject and an outside subject but also put in some minimal 14 quidelines which would require that it be spent in some dif-15 ferent direction, such as the supplying general paid possibi-

16 lities for the inmate population at large. I don't think that 17 this -- I think probably presently it would run into, in 18 particular states, some either administrative policies or some 19 legislation but that is not insurmountable either. Those 20 things are very, very quickly changed.

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I think that this should be a part of the minimal condition, that they break through some of this misuse of inmate funds so that they require a much more equitable use of the inmate funds. I think this may be the impetus which would require them to do so. I think part of your question was, was 1 it settled by -- excuse me for being late. I am suffering from 2 jet lag, you must understand, because now in California it is 3 just 7:00 and I am right on time, actually I am a little early. 4 Anyway, did you settle the problem of the fantastic differen-5 tial of the pay on the subject on the outside and the pay on 6 the subject on the inside? 7 DR. RYAN: That is part of the thing you are discuss-8 ing right now.

9 DR. IRWIN: Yes, I would be in favor of not letting 10 the drug research subject be paid more than the general inmate population. However, though, going along with Don Seldin, I 11 12 would like to see a mechanism spelled out where the prisoners through time negotiate that wage upward generally, not just for 13 14 the -- but set up something that the drug research subjects 15 cannot be paid more than just what is a typical wage for the 16 prison population, with the added provision that there are 17 adequate pay slots for a high percent of the prison population 18 and then the mechanism, which I think you are absolutely right, 19 there has to be some ongoing mechanism, but I think contained 20 in this, with minor changes, particularly in provision 7, the 21 opportunity for prisoners to work and subject grievances to 22 arbitration and participative decision-making, if we add in 23 there something about and to introduce policy changes or to 24 be involved in policy changes in the department, they would 1 25 be a force towards constantly readjusting the income, the

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general income and also addressing new problems which, you know, we cannot even conceive of. 2

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DR. RYAN: Pat wants to ask you a quick question. 3 MS. KING: I am not sure I understood something you said. With respect to remuneration, are you suggesting that 5 what is paid to subjects be the same wage paid, currently beind 6 paid to people who do other kinds of work in prison and that 7 the difference between that wage and whatever wage a subject 8 would receive on the outside, then we could worry about? I 9 want to make sure I understood you to say that, so I can ask 10 you a further question. 11 DR. IRWIN: Yes. I think, Don, you mentioned there 12 is a problem in having the drug companies pay outside subjects 13

whatever, \$20.00, something like that, and then pay prisoners 14 \$2.00. They argue that they do so because they don't want to 15 have the incentives so intense. But that still should follow 16 because they are getting by so damn cheap. So, make them pay 17 \$20.00 but \$18.00 goes into a fund. 18

MS. KING: That is not what I am asking, John. I 19 am asking if they pay 25 cents a day to clean the prison yard, 20 or 10 cents a day to clean the prison yard, and \$2.00, however 21 they do it, hour, day, whatever, for participation as a sub-22 ject, I didn't understand what you meant to do about that. 23 Did you mean to leave that discrepancy in the prison or are 24 you suggesting that what is currently being paid goes down to 25

2 That part wasn't clear. I understand what you mean by the 3 \$18.00 difference. DR. IRWIN: I am not clear on the other side, either. 5 It is my assumption that most prisons are now paying something 6 like \$2.00 a day for their jobs. 7 MS. KING: Well, it is my assumption that even though 8 drug companies have been very careful and others have been very 9 careful not to make it look too much like an enticement or 10 coercion for participating in research, that the rates for 11 participation as subjects are higher than other prison indus-12 tries. 13

DR. IRWIN: That varies from place to place and I 14 think that that should be addressed. 15 MS. KING: Well, to the extent that it exists, would 16 you tell me what you would plan to do with that? 17 DR. IRWIN: I think it should all be brought up to 18 some -- then that should be stated, that the general pay, it 19 should be stated in there that there should be the establish-20 ment of some minimum for all these pay --21 MS. KING: This is not comparability, John, that is 22 why I am really pushing. I understand comparability but com-23 parability to what? Do you bring down the research that is 24 going on, down if there is a difference? Do you bring it down § 25 to what is being paid elsewhere? Do you bring what is being

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the level of what is being paid for other prison industries?

1 paid elsewhere up to what you are currently paying? That is 2 what I was trying to find out, what John had in mind.

I am going to ask him a further question, to help me clarify what he is saying. Is that were the case, why would anybody, other than through sheer boredom if there were any other prison industry available, participate in research even if we considered it low or minimal risk research? Because prisoners, their perception of the research might not necessarily be that, even though scientifically we might say that. We might say, what would be the incentive for the prisoners to participate at all? Over the license plate factory?

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DR. RYAN: Please, let us keep the transcript clean
so that it will be valuable to us. Pat, you have the floor
for a minute. Are you done with your question?

MS. KING: I was going to ask him a question because 15 I am talking about perceptions and not what may actually be, 16 17 that in talking to the few prisoners I talked to, sometimes 18 their perceptions about what risk they are taking may vary from indeed, the risk that they are taking, the actual risk that the 19 taking, so if it was the same in terms of making license 20 plates as participating in research protocol, assuming that 21 22 the health care facilities are otherwise the same, all kinds 23 of things that we have been talking about doing, I want to know why would anybody participate now? 24

MR. GRAY: May I answer? The study actually provided

some data on that. 2 DR. RYAN: Brad, do you want to respond, please? 3 MR. GRAY: Yes. Ninety-four percent of the men 4 participating in research --5 DR. RYAN: Pat, he is answering your question. 6 MR. GRAY: Ninety-four percent of the men who were 7 participating in research had other prison jobs, which means 8 that they could participate in research in addition to doing their other prison jobs which means it is additional money. In 10 other words, you are not operating with a zero sum game. It 11 does not mean that if you are in research, you cannot do your 12 prison jobs. Many of the tests are walking around tests and 13 so forth. 14 DR. RYAN: Dr. Jonsen. 15 DR. JONSEN: I think this is really a futile dis-16 cussion. It seems to me that the problem of remuneration can 17 only be solved by inspecting an actual situation, rather than 18 trying to solve it in advance. My reason for suggesting that 19 is that, first of all, I think the economics of prison life 20 are extremely complex in the sense that to make their indus-21 tries competitive may, in fact, drive the industries out. 22 Because in many prison situations, as I understand it, the 23 work that is done is done for state agencies and they are sole 2 24 contracts and they are done because they are cheap labor. So, ⁸ 25 the adjustment of inner prison economics would seem to me to

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be a very delicate business and you would have to know very 2 carefully, you know, what kind of competition you were standing 3 up against in a particular situation, so I worry about trying 4 to make judgments prior to looking at the precise, real, exist 5 ing prison economy before I made a rule.

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The second thing is that the research situation seems 7 to me not to be comparable in a variety of ways to other kinds 8 of industries. For example, it is seasonal and occasional, 9 whereas license plate factory work may be steady work. Book 10 bindery work may be steady work, whereas somebody might volun-11 teer twice or three times in the course of year for protocol 12 or get on a protocol only in occasional situations. That is probably not in itself a life-supporting way of living in 13 14 prison, although it might be very advantageous.

15 Thirdly, the data that we had yesterday indicated some figures as to what prisoners were being paid for partici-16 17 pation in single protocols. That was not broken down in cer-18 tain ways that might have been more helpful to us, now that 19 we are in this guestion. But it did appear to me that the 20 wage rate was not unlike the rates that I usually see on pro-21 tocols that I see for free living volunteers. Now, I would need to look at that much more carefully but it didn't look 22 23 terribly different and I imagine the major savings for spon-24 sors of research come not so much from payment to individuals, a 25 but from savings and overhead, whereas you might have to

hospitalize free living volunteers for a period of time to do 2 certain drug studies which is very costly to do it in Moffit Hospital. That is not so much the case at Vacaville and the savings are largely in overhead, rather than direct remunera-5 tion. So, if what I say is the case, then I would be very 6 hesitant to say anything in the general recommendation except 7 to say that the accreditation board or whoever is going to do it, should be assured that there are fair systems of remunera-9 tion which take into account such factors as what is paid to 10 outside, free living persons, what is paid for other industries 11 within the prison because, you know, you might say you could reduce it all down to the 25 cent a day thing if you made a 12 13 general rule, and mechanisms whereby the money can be distri-14 buted in ways which make it less coercive than it might be. 15 In other words, I am just suggesting that here, rather 16 than try to solve the remuneration problem this far removed 17 from the actual problems, that we state our position very 18 generally and leave it to accreditation board to examine par-19 ticular situations. 20 DR. RYAN: Dr. Cooke. 21 DR. COOKE: Well, I tend to agree with Al a little 22 bit. I would like to ask John Irwin a question. We have some

23 kind of a system in which the rest of the prisoners benefit. 24 I am troubled that this puts an awful lot of pressure on that 25 subject to stay in the protocol. I am getting X number of

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T dollars for the fund and I want to bow out. How well is that 2 going to sit with my buddies back there who are getting some 3 benefits from my blood donations and so forth? Is that a 4 problem?

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5 DR. IRWIN: Well, I think there are two sides to 6 that. One is one I think is a positive side, shifting the 7 motivation to altruistic motivation, that is, doing it because 8 it brings about some good isn't a bad thing. We have all been 9 worried about the pursuing individual selfish motives and so 10 on. I guess you are talking about the extreme of that, where 11 a person is really being coerced not by his altruism, but by 12 his peers, that there would be extreme criticism on the part 13 of one's peers. I would see that handled in a different way. 14 The balancing factor, incidentally, in prisons, there 15 is the strong dictive of do your own time, of allowing people 16 to pursue their own -- in fact, that has been one of the big 17 problems in prison, the strong rule of don't call on me to 18 help, it has all kinds of sides. It has a side which means 19 tolerating extreme deviance, it also means don't interfere with 20 another person's exploitation of others and so on.

21 That would balance that, but I would like to hypo-22 thesize and hope that I am right, that a nice balance between 23 some altruistic motivations and just a little bit of peer pressure to keep going and some system of rotation on it, where 24 25 a person could say, okay, you know, I have done two weeks on

it and it is somebody else's turn. If there was an adequate prisoner organization, I think that would be the one that would 2 occur more likely.

It wouldn't be a bad deal. If they saw that as a 5 source of funds, sharing the work a little. 6 DR. COOKE: Isn't that kind of idealistic? I would 7 think if this guy is earning a fair amount for the fund, I 8 think there would be a lot of pressure from his friends back 9 in the prison to keep going in those experiments. 10 DR. STELLAR: If he doesn't, somebody else will step 11 into that slot. 12 DR. RYAN: Excuse me. Bob, I think that if there 13 adequate activities, if it was a requirement that all prisoners 14 participate in some activity, if the pay were equal, there 15 would not be a selective pressure to do one or another form of 16 such activity to redound to the general good, any kind of 17 activity. The pressure would be on prisoners not to be free 18 loaders but to communicate, to participate within the society. 19 As long as you don't single out research as receiving more 20 money and as being something that you could coerce prisoners 21 to do for that reason, but if the activity was there to do 22 other things, then I don't know ---23 DR. COOKE: I think you have to go back and read the 24 essays on the prisoner culture. I must say that may be a ² 25 loaded description but I cannot see all this altruism operating

and so on unless there is an awful change in that culture in a heck of a hurry.

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3 DR. RYAN: Well, altruism, as you use it, is in the 4 eyes of the beholder and very often there are group pressures 5 for the general group good and you may want to call that al-6 truism or you may just want to call it peer pressure. But the 7 practical consequence may very well be the same. Mr. Calhoun.

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8 MR. CALHOUN: I guess I am rather worried about this 9 point and I wanted to ask John a question, and a couple of 10 observations along the way. One, this whole process of accred 11 tation that we talked about is a very lengthy, very complex 12 and very detailed process that we are trying to outline here. 13 I wonder if we are not in a way saying that we cannot, or can 14 we actually regulate research in prisons. Maybe if we make it 15 so difficult, you know, in terms of this accreditation process 16 we are going to end it. Because I have a sneaking suspicion 17 that there is no way you can implement what you are talking 18 about, for several reasons.

19 The nature of the institution, the nature of the 20 political arrangement that is around those institutions, would 21 not allow you to make revolutionary changes in the system by 22 employing a device which is a minor device in most institu-23 tions, and that is biomedical and behavioral research in the 24 institutions, to get at the changes that we would all like to 25 see. That we may be, in fact, spending a great deal of time

talking about a process that has no applicability to the real 2 world. Now, saying that, I would like to ask a couple of 3 other, ask you to comment on that, John. In addition, if we 4 are to go with this statement, which I must somewhat disagree 5 with, also add two other things. One is an equal opportunity provision to participate. I think that some of the inmates ó stated at Jackson that the control over access to participation 8 was limited enough in some respects by prison guards or others who had some sort of sway over how people got involved in 10 participation.

11 The other thing that I wanted to raise is in terms 12 of pay rates at these prisons vary from job to job. Are we 13 suggesting that research pay be balanced at the highest point 14 in terms of the highest paid position at that institution or 15 are we suggesting that it be somewhat above that and that the 16 excess funds be drained off in terms of the actual paycheck to 17 the inmate and put in some sort of special fund? I don't think 18 those conditions have been adequately spelled out in terms of 19 how you would define those sorts of things. 20 But I would again say that I think the process that 21 we are going through now is, in a sense, one that may be doing 22 something that we perhaps not at this point intending it to do ę 23 and that would be to end it, end the research studies. 2 24 DR. RYAN: John Irwin, do you want to respond? ² 25 DR. IRWIN: In regard to your first expressed

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reservation about the likelihood, the danger that this would result in just cessation of the drug programs, rather than 2 changing the prisons, I feel very strongly that this may sound 3 like sweeping or revolutionary changes but it is not true, .4 5 really.

When you look at these, a lot of these things have 6 been recommended very, very strongly by a series of commissions 7 which have looked at the prison world recently. Several prisons 8 9 have made major steps in the direction of implementing some of these. In Washington, for instance, there is a group which 10 some of you may be familiar with, it is the Center for Correc-11 tional Justice with Linda Singer as its head, who has written 12 a book with Ron Goldfarb on this issue, who is now -- in fact, 13 14 didn't they testify before the, they didn't? They didn't, strange. Anyway, they are going around the country trying to 15 sell a grievance mechanism which they have introduced in a 16 couple of states. 17

As I indicated briefly yesterday, California almost 18 accepted something very, very similar to this, spelled out a 19 20 little more in detail. We still think that we will have it in a year. As Ken Ryan mentioned yesterday, it was his imprest 21 sion that the prison situation because of the extreme criticishs 22 of recent years, the concern over it, is in a state of flux. 23 24 There are, of course, a lot of pressures which are coming to bear upon it, some of which are very conservative, who want to 25

keep it back in the old status quo, the old form of operation. There is a fantastic opportunity for it to make major steps right in this direction. I don't think it is that farfetched.

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DR. RYAN: Karen, please. 5 DR. LEBACQZ: Yes, I want to reiterate a couple of 7 points that have been made. One was made by Lee and that is | that it is my understanding that the pay for different jobs in 9 prison differs, so it is not going to be a simple matter for 10 us to say that the pay for research equal the pay for other I jobs. The other point was made by Al and that is that, as I understand it, the difference between what a drug company or 3 some other organization would have to pay for free living volun-14 teers and those in prison, a major portion of that cost does is come in terms of overhead, not in terms of the actual pay rate 16 to the individual.

Therefore, there will always be some inequity, even 17 18 if we require that prisoners be compensated at the same rate of persons on the outside are. There is still a sense in which 10 the prison population is a cheaper labor pool for the drug 11 company or other organization. That brings me, then, to the 22 concern that Al raised about whether we ought to be trying to 23 be very specific on these matters or whether we ought to be general. I move in the direction that he is suggesting, that 24 25 is, that we cannot ourselves get to the point of setting dollars

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1 and cents rates for things. There is an additional problem, by 2 the way, which is that when we talk about compensating for 3 research in terms of the time involved, I don't know whether 4 time there means the time it takes to put a skin patch on 5 somecue's arm or the time that they walk around the prison with 6 the skin patch on their arm, and that is going to be quite 7 different.

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So, there are other kinds of problems like that. It 8 does seem to me, therefore, that unless we were to get purpose 9 ly bogged down in all these specifics, that we are going to 10 have to move in the direction of being general, but I am not 11 happy with saying that we should simply leave it up to some 12 accrediting board or other agency to make these determinations 13 because they will then get bogged down in all the things that 14 we are getting bogged down in right now. 15

I think it would be most helpful if we could at least 16 find some of those rules or principles, if you will, some level 17 principles, that would be helpful to such accred ing agencies 18 or boards that would have to do that, so that we make it clear 19 what it is that we are striving for. Where does equity lie 20 in-between paying people for research, what they would get 21 paid for other things in the prison and the fact that all of 22 those rates will be so much lower than what people on the 23 outside would make? We need some better specification of what 24 equity requires here, I think. So, I am not happy either with 25

getting into all the specifics or with saying we just make a general statement and then leave it for somebody else to do. I think we are going to have to do some of the hard work in 3 4 terms of saying what equity is all about. 5 DR. RYAN: David Louisell, I will call on you. DR. LOUISELL: Well, I understand Dr. Jonsen's concern about trying to be too specific on an abstract level, but I 7 also saw in your remarks a great danger that we could be interpreted to imply recession from the principle of equal remuneration inside as prevails outside. I think we have got to be very clear and explicit and avoid the possibility of 11 | misinterpretation there. I admit that Karen has introduced an important cost-accounting proposition because even though you 13 assume an equal rate of remuneration to the individual inside 14 15 and outside, there is also the factor that Karen pointed out, of greater economy by reason of the inside people being inside 16 17 However, that is a mechanical or more or less costaccounting proposition and that can be taken care of as a 18 matter of detail. But I submit we have got to be abundantly 19 20 clear and not permit this to slip away, that the rate of remuneration on the inside is the same as on the outside, even though not all of that amount of remuneration immediately accrues 22 to the disposable income of the inmates. 23 DR. RYAN: I am going to let you respond and then 24 we are going to break for coffee for 15 minutes and start with \$ 25

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Dr. Seldin afterwards.

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DR. JONSEN: I want to affirm that. I didn't want to 2 to be thought, either, that I wanted to be so general that 3 we were going to pass off the problem or that I wanted to 4 retreat in any way from that comparability, but I just want to 5 state that what occurs to me now to be the basis for that. 6 I really had thought of it before. I assume that for most 7 situations in the economy if somebody finds a rare situation 8 that perfectly suits their needs, they are of centimes going to 9 have to pay more to use that situation. If it is a rare 10 situation, I think our form of economics means that the price 11 is usually higher and in this sense the prison environment, 12 in fact, does provide, if the drug companies are to be believed 13 in this respect, a peculiarly suited environment for certain 14 kinds of their testing. 15 Therefore, there is really no reason in our economic 16 system why it ought to be cheaper. 17 DR. RYAN: With that note, why don't we re-convene 18 at quarter to eleven? 19 (Brief recess.) 20 DR. RYAN; I would like to re-convene. We are going 21 to break for lunch at 12:00 noon and re-convene at 1:30. That 22 will give us an hour-and-a-half in the afternoon to finish the 23 rest of our business. So, we are going to try and keep to the 24 schedule if we can. Dr. Seldin, do you want to lead off, please ğ 25

DR. SELDIN: I want to return to what seems to me a critical issue. It has to do with item 7 in which the term "opportunity," to my mind, is not sufficiently precise to know how to translate the opportunity into something that is real. 5 I want to suggest that in addition to the two boards that have been referred to in this report, the institutional review board 6 and a national or regional accrediting board, in addition to that that there be a review and grievance committee. 8 9 I tried to work up some sort of wording with John that might be suitable to express this in a rough sort of way 10 11 John, perhaps you would want to suggest some formulation of 12 th.s.

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13 DR. IRWIN: Yes, I think that Don and I are thinking along exactly the same lines and, incidentally, it is a direc-14 tion which many other persons have traveled down. I think we 15 are coming to something which is very important and I agree 16 17 totally with your concerns over the way this is stated. The opportunity for prisoners to organize is really very weak and 18 that condition can be fulfilled in a variety of ways which are .19 unsatisfactory for the spirit of this document, I think. 20 What it takes to give it meaning and force, for it 21 to accomplish what needs to be accomplished, is the access to 22 a third body, a grievance or review kind of body which is made 23 up of a variety of community and prisoner representatives, 24 which should be spelled out. There are some minimum ranges of \$ 25

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	1	it that should be spelled out, the prisoners, of course, and		
	2	rights advocacy groups, ethnic and racial representation and		organize, I think is
	3	so on. I would like to see us re-word the sentence, it will	2	DR. SELDIN: Yes, that would
	4	take a little work, so that the two ideas are contained.	3	would facilitate that sentence.
	5	One is the right for the prisoners to have the	4	DR. IRWIN: Don, I think that
	6	organization, the other one is for them to have some regular	5	agree with that in total. It contains,
	7	contact with this structure.	6	couple more words about it, when we wer
	8	DR. SELDIN: You don't think that formulation	7	able set of values which would prevent
	9	DR. IRWIN: Let me read you the way it is.	8	to prisoner groups in California, which
	10	DR. RYAN: Please read it.	9	permit drug research to exist in prison
	11	DR. IRWIN: To facilitate and I cannot read this.	10	this is exactly what came up. This is
	12	DR. RYAN: Okay, I think you can work on this.	11	the big discussion that was on, the exi
	13	DR. SELDIN: Well, no, it is just something to be	12	review mechanism and its composition.
	14	specific, Ken. Everybody is saying, why don't you say something	13	tion that was suggested in our meeting
	15	specific? This is an attempt to be specific. If you want me	14	was very much like this.
	16	to work on it, I will work on it.	15	DR. RYAN: Dr. Cooke.
	17	DR. RYAN: If you have it ready to read to us at this	16	DR. COOKE: I am going to take
	18	moment.	17	which I think will get some support fro
	19	DR. IRWIN: A review and grievance committee separate	18	pants but is totally in opposition to t
	20	from the IRB and the national-regional accreditation bodies	19	going. What I think we are doing right
	21	must exist. Such a committee should be comprised of prisoners,	20	a little bit like fighting the Viet Nam
Auc		representatives of prisoners, ethnic and racial advocacy groups	, 21	ing to make ways of fighting the war be
Reporting Company	23	and the public. It should meet at regular intervals for pur-	22	is, should we be in it in the first pla
sporting	20	poses of review and grievance hearings. I think something	p 23	I think that is probably, we
BOWERS RE		in conjunction with that paragraph, coupled with the right to	24	place for two reasons. One, I think th
B	25	in conjunction with that paragraph, coupred with one ray	25	improve prisons. I am not against that

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hat that would do it. I hs, if I may just have a vere working on an acceptnt drug research according of would allow us to sons in our own conscience, as the final, and this was existence of this outside You know, the composing after a long discussion

ake, again, an approach from two or three particio the approach that we are ght now, Mr. Chairman, is Nam war. Everyone is trybetter but the question

we are in it in the first there is an effort to nat but I think this is a terrible vehicle for it. Second, to let prisoners somehow earn more money. I really believe those are the two things that 2 are underlying this accreditation approach and I would like to 3 go back and ask what did we do when we were talking about fetal 4 research. What we did in fetal research was ask a question, 5 are therealternative ways of carrying out the research so that 6 the fetus does not have to be used. 7

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And we said that we would allow fetal research only 8 under circumstances in which there were no alternative means. 9 Now, we have lost sight of that in regard to the prisoners 10 because I believe we are trying to be fair to the prisoners 11 to allow them to earn some more money. And we would like to 12 improve the prisons. Now, what I would like to suggest is that 13 we would like, I would like to propose that we not use prisoners 14 at all unless there are no alternative means or unless there 1.5 are equal number of non-prisoners participating in research 16 activities of a particular type as prisoners, in the same sett-17 ings, et cetera, to use the comparability of treatment as the 18 test of the freedom of these people in the real world. 19

I don't believe the accreditation thing is going to 20 work at all. I think limits in terms of budgets and so forth 21 that are imposed by legislators representing the public view 22 will keep any of this from happening and I would like to suggest 23 this other approach completely, rather than trying to dot the 24 i's and cross the t's of how to make better the accreditation 25

process.

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DR. RYAN: I think the general thrust of your recommendation, Bob, was, however, research should not be done in prisons on prisoners. Is that correct? DR. COOKE: Unless there are no alternative means, right. DR. RYAN: But the last one is sort of a given.

and so what you are suggesting is that research not be done on prisoners in prison. 10

DR. COOKE: Unless there are no alternative means. Now, you can say that, Ken, that there are alternative means or alternative means for some projects. I can visualize circumstances where it might possibly be necessary to use prisoners and then that would be reviewed on its own merits, et cetera, by an appropriate body. But what I am saying is that as along as there are alternative means and we know what they are and they can be done, that is what we should encourage. DR. JONSEN: Mr. Chairman? DR. RYAN: Yes.

DR. JONSEN: I would like to say that I simply couldn't accept Bob's proposition. If he could argue no prisoner research whatsoever, he might be embarking into that position. But if he appends "except there be no alternative," I simply couldn't accept that because if there were any research

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There are alternative means that have been documented for us

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	1	whatsoever done in a prison, I would require the things that		1	because of
	2	we are working on now as the conditions under which any sort		2	list out so
	3	of research be done in a prison setting. Because		3	ditions are
	4	DR. COOKE: All right. That doesn't, that in no way		4	closely res
	5	all you are saying is that if there are no alternative means		5	and freedom
	6	found, to go ahead and do it in the prisons we have to have		6	could th
	7	all of that, that is okay.	and the second	7	there is to
	8	But I am just saying that if you do all those things,	and the second	8	then sugges
	8	I am not satisfied that you are really going to change the		9	В
	10	prisons that much, so that that is adequate protection and	11 MAR 100 MAR	10	lem really
	11	therefore, I guess I am saying you shouldn't do it on prisoners	•	11	wholehearte
	12	DR. RYAN: Mr. Turtle.		12	drug compan
	13	MR. TURTLE: Well, I think I would like to speak in		13	officials.
	14	favor of the position that Bob Cooke has taken. I too gather	and the second	14	the drug co
	15	that there really has been no justification for research in	ter of the Article	15	of providin
	16	prisons other than the arguments in favor of reforming prisons	one reaction states the	16	they did th
	17	and that seems to be some, you know, extrinsic value that we	a series and a series of the s	17	state prisc
	18	are dealing with. On the other hand, I think we have been able		18	ones to pus
	19	to identify certain things in the prison environment or setting	An air an ann an ann an ann an ann an ann an a	19	prison and
	20	which give us great concern about allowing research in prisons		20	available t
<u>×</u>	21	on prisoners. I think some of those have been identified and		21	the constra
Reporting Company	22	situations set forth.	'n	22	the price t
oorting	23	What I would like to say or see is a formulation which		23	reforming p
WRIS REF	24	says that based upon the world as it is now, we would say that	an a	24	again it ha
B D D	25	there ought not to be any research in prisons on prisoners		25	

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the following conditions that exist in prisons and me of these conditions. Say if and when those conalleviated and the prison situation begins to more emble the outside society in terms of alternatives , then under certain circumstances at that time we e conditions that lead us to the conclusion that be no research having been eliminated, we would t that the problem be re-considered. ut I think we have to deal with what is. The probis, what is going to happen in the interim? I dly agree with Bob. It is not a problem for the ies and it is not a problem for the stated prison In most instances, no concern, really. I think mpanies would be willing to pay the price in terms g remuneration to prisoners and making sure that eir part to make the program work. I think the n officials would, in all probability, be the first h for prison reform and added alternatives in the so on and so forth. The real problem is the funds o undertake prison reform on such a mass scale and int will be the unwillingness of the public to pay hat we are talking about, the economic costs of orisons in general are a price that over and over is been demonstrated states are not willing to pay, that is, the legislators and the people. The bond issues have

all been voted down.

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Now, that means that over the next, you know, five 2 or 10 years we may have situations in which accreditation is 3 requested because somebody most closely approximates the con-4 ditions that we are setting forth or is at least working in 5 that direction or hasn't done anything, really, to retreat from 6 che progress that they had previously been making in that 7 direction and that, to me, would be unacceptable. I think we 8 identified the problems and we have to come to a conclusion on 9 what we know today. My conclusion would be no research in 10 prison on prisoners. 11

If the conditions are eliminated at some point in the 12 future, I think any reasonable man would re-consider the problem. 13 DR. RYAN: Or a woman. But you haven't really shared 14 with us in our discussions up until now and the question is 15 not whether or not the conditions exist now which would allow 16 research, but whether or not after setting this as an accredit 17 ing scheme, if this were achieved, would we allow research? . 18 MR. TURTLE: Why does the problem have to be posed 19 that way? I think that is the wrong way to pose it. 20 DF. RYAN: I know but we have been talking for a 21 day-and-a-half and we thought it was the right way to pose it. 22 Now the question is, given that, would you then not allow 23 research if you had these conditions in place? Now, if that 凝 24 is the case, then we can finish our discussion very, very 108 25

quickly.

2 MR. TURTLE: I think we are discussing the same 3 conditions and I think the only difference, really, is what is the position in the interim? 5 DR. RYAN: That is another question. 6 MR. TURTLE: But it is a very important question to 7 me. I think we could all agree upon the problems that we 8 perceive in prisons now and the conditions we would want before 9 research could be allowed. The question really is what happens 10 between now and then. 11 DR. RYAN: Okay, that is another issue which the 12 Commission could address itself to and hasn't yet, Bob, and 13 that is an important issue. Dr. Louisell. 14 DR. LOUISELL: In the interests of brevity, I would 15 like to adopt verbatim Al Jonsen's statement. If Bob Cooke 16 were urging us totally to abolish research in prisons, I would 17 be within a hair's breadth of supporting him. If, however, 18 he insists upon the alternative, "unless no alternative means 19 are available," then I, like Al, feel compelled to the specifi-20 cation, even for the rare incident of the very conditions and 21

limitations we are now talking about. 22 DR. RYAN: Karen. 23 DR. LEBACQZ: I just want to submit that it seems to me that prisoners are in a very different situation than 1 24 fetuses are. Among other things, by and large they are adults \$ 25

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	٦	who can speak for themselves and it seems to me, Bob, that you			
	2	haven't really come to grips with that question in making your	ļ	1	precipitous but I want to re-fe
	3	proposition. I don't understand why you would begin by saying		2	again, rather than off in these
	4	that no research should be done in prisons unless it is because		3	here trying to outline what I
	5	you think that the conditions in the prison are such as to		4	personal feelings inside about
	6	render informed consent impossible or whatever. And if that is		5	comes of some of these issues,
	7	what you think, then those are the very conditions that we are		6	report that we want to have, an
	8	trying to address here in order to say that if we could change		7	troversial things, should look
	9	those conditions, it might be possible to do.	•	8	The Commission has ad
	10	So, I would be very surprised, then, that you are not		9	in prisons and research on pris
	11	in favor of the general thrust of what is happening.	-	10	things. The Commission has det
	12	DR. COOKE: I have no confidence in your accreditatio	n		want to propose is that we stop
	13	process.		12	It is a bad word. That is not
	14	DR. LEBACQZ: Well, I don't have any confidence in		13	done something different. We h
	15	the process, either, but we haven't gotten to that. What we	anger of the state	14	standards and principles becaus
	16	are talking about now is what would be the conditions that	and the second	15	agency nor do we presume to be
	17	would make it necessary	an an official solutions	16	to nitty gritty kinds of detail
	18	DR. COOKE: No, these are live processes. There are	and a tradition	17	different kind of level, so I w
	19	no results on this piece of paper. You have got a lot of		18	the term "accreditation" and an
	20	different things, you are going to have regular access by		19	thereof.
	21	prisoners to means of communication and so forth. I think it		20	That, one, the Commis
	kg 22	is a lot of meaningless stuff.	-	21	following sets of standards, pr
,	g 23	DR. RYAN: Pat King.	Anoquo	22	blah, to the degree that they c
· · ·	Auduon Bullioday 23 24 25	MS. KING: I am going to try to do something that I	The C	23	majority or all or less than al
	25 a	hope is not meaningless. I certainly hope it is not	ers Repo	24	permit research in prisons. If
			BOW	25	ly meeting that model, so be it

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focus this again and get us focused se directions. I have been sitting think a report, given my own it how I may feel about the cur-, and it seems to me that the and I am going to state some conk like the following.

addressed the issue of research isoners, they are two different etermined, and the first thing I op using this word "accreditation." t what we are doing. We have have been attempting to specify use we are not an accrediting e one and we are not getting down ils. We have been dealing at a would love to abolish all use of anything that is a derivative

ission has found that given the principles, blah blah blah blah can, if they can be met, a 11 the Commission would then If there is no institution currentit, then you cannot do any research

1 in prisons until you find something.

Two, it seems to me that Bob's idea is not inconsistent with what I was proposing.

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DR. RYAN: Bob Turtle, you mean?

5 MS. KING: Bob Turtle and Bob Cooke. He won't vote for the first part of my proposal but you could then have a 6 7 section that said research on prisoners that would also permit 8 research on prisoners outside of a prison setting, given the 9 following set of circumstances and conditions. It would seem 10 to me that the beginning of this report or at the end of this 11 report the Commission -- my controversial statement -- would 12 therefore call for an indefinite moratorium on research on 13 prisoners and on research in prison until such time as it could 14 be determined that these conditions or standards have been met and in addition, we could have a request for someone to 15 16 specify or break down the standards in greater detail and that 17 if we want accreditation, we are not the agency to do it, we 18 are not the commission to do it, that we call for somebody to 19 take what we consider basic principles and break them down 20 into very concrete and quantifiable standards, which we are not 21 going to do here.

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It is the model, if we stop and think about it, that the Federal Bureau of Prisons just took. They are essentially saying, I don't think they go far enough, but they are essentially setting out their perspective of the standards,

principles and conditions they have determined if their insti-2 tution does not meet those standards and they have decided to 3 call a moratorium on what they are doing. If we could concentrate or agree that that is what we are trying to do, that even satisfies me in terms of my own 6 quarrel -- I may take a more extreme position than some people and that, to me, is a middle road position, that I have just 8 stated, around which we may be able to get some agreement, if we would focus it that way. Maybe we can bring to Bob's along 10 with us. If they vote down the first part, fine, but at least if we concentrate that that would be our outline of where we 12 are going, I think we may have it. 13 DR. RYAN: It was my assumption and that is why, when 14 Bob Turtle re-stated it, he started out the way Bob Cooke did, 15 because Bob was for no research except under conditions which 16 then made it untenable because we wanted conditions in prison, 17 Bob Turtle said, look, if you get these conditions I don't think 18 you can get them, but if you get them, then I would be willing -19 to consider research and I think Pat King has put it now in 20 the --

MS. KING: I said something a little bit different from Bob, in all fairness to him. He would like to say conditions are bad, no research in prisons, without, if I heard him correctly, attempting to specify standards under which the majority of us might permit it, even if those standards are

1 impossible to reach. He said we posed the question wrong and 2 I understand what he meant about how one poses the question 3 may be critical. I suggest that I prefer proposing the question the way we have proposed it to say the conditions are bad 5 and leave it alone. It seems to me to do nothing but state 6 the obvious.

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7 MR. TURTLE: Just to correct that. I would include 8 these seven conditions. I would say in reality the reason that 9 we, you know, are not allowing research is because these con-10 ditions do not exist, one, two, three, four, five, six, seven. 11 And if they did, you know, we would think that under those 12 circumstances --

13 DR. COOKE: There may be others in addition to these 14 seven.

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Mr. Sugar St.

MS. KING: Well, yes.

16 MR. TURTLE: I think we have a duty to identify the 17 reasons we don't at the present time feel very good about 18 research in prison or research on prisoners. But once we do 19 that, I think that we can then formulate, you know --

20 DR. RYAN: I think we should also be aware that we 21 are making recommendations to the Secretary of HEW and so on 22 and so forth with respect to the conduct or support from the 23 federal system and that we would have to ask ourselves to what 24 extent should this impinge on state systems, county systems and ີ້ 25 what devices there may be for that to return to the Congress

with recommendations. Yes? 2 MR. GRAY: I would just point out that I don't believe the Commission at this point has in its hands the documentation to support a statement that says these seven conditions do not - 5 exist in any prison. It is one thing to say that they should exist and then we can see the extent to which they do. But to say that they do not exist anywhere, implying that you know they do not exist anywhere, and I don't believe that we have 9 that documentation.

MS. KING: I didn't say that, I said --MR. GRAY: That is what Bob Turtle said. MR. TURTLE: No, I said these are the things that concerns us based upon what we have seen to date. These are the conditions that seem to exist in prisons which give us difficulty.

DR. RYAN: And now, just to throw other Commission members of a mind with respect to this that it is worthwhile trying to grapple with, you didn't like the word "accreditation," grapple with the kinds of standards that we would like to see in a prison if research is going to occur, that unless those conditions are met and identified by an appropriate body, our recommendation would be that the Secretary should not support, approve or conduct research. I thought that was the direction we were going.

Are all the Commission members of like mind with

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	1	respect to this? Bob Turtle, this might very well end up with		1	
	2	the Secretary being unable, if he accepts our recommendation,		2	eliminated, then we would have no obje
	3	to support research in prisons until he could satisfy himself		7	DR. SELDIN: But that is not
	4	that they were met because that would be our recommendation.		3	
	5	DR. COOKE: I think the weight is so I think you		4	reiterate the point, that a moratorium
	6	are minimizing the differences here between the Turtle approach		5	standards can be scrutinized prison by
	7	and the rest of the approach. I really do. They are really		0	qualify. If it turns out that no pris
	8	saying the situation is such that the burden of proof has		7	tially this is neutral, Bob, to my
	9	to be on proving that the conditions within prisons are abso-		8	to endorsing or criticizing. It simpl
	10	lutely changed before we have anything going on in the way of		9	is a major problem and these are the s
	11	research. You are saying that the research is going on and if		10	
	12	we can do these things it is okay to continue.		11	if research is done.
	13	DR. RYAN: I didn't say that at all.		12	The moratorium would take ca
	14	MS. KING: I didn't say that either.		13	said, of the two points you both make.
	15	DR. COOKE: That is the weight.		14	DR. RYAN: Karen Lebacqz.
	16	DR. RYAN: NO.		15	DR. LEBACQZ: Yes. I am ver
	17	DR. COOKE: I think the impetus so far, the approach		16	what Pat is proposing and the problem
	18	has been much more supportive of research in prisons. I must		17	Bob, is very simply what Brad said. W
	19	say that is the flavor of it, at least, than the Turtle approa	ch	18	don't have data on every prison enough
	20	which says no research in prisons.		19	should be done because of all these di
	21	MR. TURTLE: Because of one, two, three, four, five,		20	to say it the other way around. We hav
7	22	six, seven.		21	standards that would have to be met be
E O O	23	DR. COOKE: Right.		22	done. We can then call for a moratori
ortin	24	MR. TURTLE: And a statement at the end that basical		23	until such time as an appropriate body
30Wers F	25	ly says were one, two, three, four, five, six, seven to be		24	other body, can make the determination
		TY Says were one, two, three, rour, rive, six, seven to be		25	institutions that meet the standards t

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t what Pat said. If you ly fair to say that to m be declared until these y prison to see if they son qualifies, then essennind, anyway, with respect ly acknowledges that there standards in terms of which must be satisfied

are, to my mind, as she

ry much in support of with doing it your way, We don't know because we h to say that no research ifferent things. We have ve to say these are the efore research could be ium since we don't know y, not this one, but some n whether there are any that we have set and that

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	1	seems to me to be the way that we have to go. We cannot say	n de la composition de la comp		
	2	there may be no research because there is no institution that	1 S. 		MR. TURTLE: I really don
	3	meets these seven or ten or however many items, because we		2	see it written out. It brings us to
	4	don't have the data to say that.		3	and Pat suggest.
	5	We have to do it the other way around and I am very		4	DR. RYAN: We are not play
	6	much in support of what Pat has proposed as a general way for		5	MR. TURTLE: Well, we are
				6	we are writing standards and you ge
	7	us to move. It seems to me to make eminent good sense.		7	lems again, the burden of the proof
	8	DR. RYAN: Where do we stand on this Commission-wise?		8	going forward in any particular ins
	9	Are we of a mind about this or not? Can we take a straw vote?		9	DR. RYAN: You are making
	10	It involves a tremendous amount of work to develop these		10	conditions don't exist unless you kn
	11	accreditation, these		11	research shouldn't occur because pr:
	12	DR. COOKE: So, let us take a straw vote.		12	You have to define what is bad about
	13	MS. KING: Let us take a vote.		13	
	14	DR. RYAN: These standards now, Pat made a sugges	-	14	MR. TURTLE: Well, define
	15	tion and let me re-phrase it and liscen to it very carefully			what is good about them.
	16	because, and that is, that we ask that research not go on un-	Alter Money America	15	DR. RYAN: And we are try:
	17	less assurances are made that these conditions exist and that		16	what conditions we would say would b
	18	we ask for a moratorium until that determination is made and		17	MR. TURTLE: The absence of
	19	that research not be allowed unless they can be realized, in		18	be acceptable. I would prefer to se
	20	appropriate language. Is that the general thrust? Who, sitt-		19	as the problems that we perceive in
				20	when those problems, if those proble
è	21	ing here, Commission members, would agree with that if the		21	are resolved, then we would, you kno
Company	22	standards were met there?		22	any different than any other researd
	23	DR. LEBACQZ: Straw vote.		23	Now, you are saying you should do th
Bowers Reporting	24	DR. RYAN: Anyone who would disagree? Yes, there		24	state the standard and I don't reall
BON	25	is just one.		25	MS. KING: I have a sugges
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't know. I would have to o the same place, as Karen

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ying with words.

e playing with words because at into very difficult proband who has the burden of tance.

the presumption that those now. You just said prison ison conditions are so bad. t those --

them, then you should know

ing to say what is bad and be acceptable.

of the bad conditions would ee the conditions stated prison research and say ems don't exist or if they ow, then it wouldn't be ch, given certain constraints. he converse, which is to ly know how I could do that. estion, Bob.

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MR. TURTLE: I know what the problem is but I don't know what the answer is.

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MS. KING: I have a suggestion, Bob, and it is one 3 4 I just made to Michael and that is, you may not like it anyway, but in the deliberations or conclusions which would precede 5 any set of recommendations that we made, I think we should have 6 a section on our perceived, our perceptions of what is bad 7 about about prison and the reason I emphasize our perceptions 8 is because I quite agree with Brad that we are very ignorant 9 about an awful lot of things. To proceed to talk about standards, 10 even though our perceptions may be skewed or our perceptions 11 may be what they are, it seems to me we have approached this 12 from a different perspective. 13

I go back to the efforts. We started with this and 14 we were really concerned about is it something special about 15 a prisoner in a prison that requires that we, perhaps, treat 16 them a little bit differently, not differently, provide extra 17 protection, is he vulnerable, is she vulnerable, and we 18 approach what are the standards and the conditions under which 19 we think it would acceptable for human beings in institutional 20 setting like a prison, what standards must be met before we 21 can involve them in research. 22

That is not to say that the research is bad. That 23 is not to say anything about what has been going on. To the 24 contrary. My perceptions about the research that has been going 25

on has not been that it has been all bad research or that it has 2 been a bad influence. It is to say we want to examine and worry about this category of persons like we are going to worry 3 about other categories of persons and attempt to set out and 4 5 lay out some standards so that our concerns can be met. 6 I think I can do that without having visited every 7 prison in the United States. I don't think I could do, Bob, 8 what you were suggesting without having spent an incredible 9 amount of time dealing with the details of prison life and 10 experiences in order to set out every bad condition for fear

11 that I might have missed some.

12 MR. TURTLE: Well, this is what troubles me. I would 13 certainly agree with Brad's point and your point that we 14 obviously don't know enough to say that all, you know, prisons 15 are bad and don't meet the conditions. By the same token, 16 we really don't know enough to know that we perceive all of the 17 problems and therefore, to say that it is okay if it meets 18 these standards, have we really missed something else? 19 MS. KING: They are minimal -- let me explain some-20 thing else -- they are minimal conditions. That is the only way we have been trying to say it. They are standards stated 21 in terms of general principles which we, as a current Commission, 22 might find acceptable research in prisons if we could at 23 least meet those standards. That is all we are saying. We 24 may have missed something, I agree we may have missed something 25

but it seems to me that by stating them as a minimal system of standards, set of standards, we cover quite a bit of territory in stating them as minimal conditions. I am sorry, I feel much more comfortable approaching them that way than from the way of listing what is bad and saying because we know these bad things or think we know these bad things, we will now say absolutely nothing and then give no guidance about what might make it permissible, if anything.

DR. RYAN: Dr. Cooke.

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DR. COOKE: I would like to take a crack at this. 10 This has gone more extreme every time I hear the arguments but 11 what I would like to suggest is the following. That because 12 there are alternative means that are quite feasible, because 13 the realities of prison support, funds to do the kinds of things 14 that are laid out here, all the problems inherent in some kind 15 of review process, and all the inadequacies and all the dif-16 ficulties, the coercive influence that exists within prison 17 groups and such and such and such, I would propose that there 18 be no research done in prisons and that the industry be en-19 couraged to develop alternative means much more fully. I 20 think that is the extreme position. That is an essentially 21 permanent no research in prisons. 22

DR. RYAN: Okay.

24 DR. STELLAR: Bob, you have narrowed it to drug25 companies now. You don't mean that, do you? What about

1 behavioral research and rehabilitation? 2 DR. COOKE: I am talking about non-therapeutic bio-3 medical research. 4 DR. STELLAR: Okay. 5 DR. TOULMIN: Which is not all done by industry. 6 DR. COOKE: But that alternative means be developed 7 by people that need to do this kind of research. 8 DR. RYAN: Of course, that is gratuitous advice. 9 If you stop the prison research, you are going to have to do 10 that anyway. 11 MS. KING: Didn't my proposal take into account that, 12 Ken? What I tried to do was to say we would find these things 13 acceptable for research in prisons and the second section of 14 the report would be we find acceptable research on prisoners 15 in the following list of conditions, under the following circumstances which, in fairness to Bob, we have not detailed. But 16 I proposed that we do that as the next step and I think that 17 18 we have to, of necessity, really, since all research we cur-19 rently know is not done in prisons on prisoners, that we have 20 an obligation to do what Bob is suggesting. 21 He may not favor the first section and I am saying that but it seems to me I would favor what he is proposing but 22 23 I want something in addition. I am not excluding what he is

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proposing. He would ban the first and I would not. DR. RYAN: I think it is a question of emphasis, what

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	1	you put first and so on. Other people want to be heard. Dr.		1	we have be freed, where the management
	2	Jonsen.	te state of the second se	1	going to be freed, et cetera. Those a
	3	DR. JONSEN; I am just wondering how Bob got so far	and the second	2	we haven't even looked at, ways of usi
	4	from where he was yesterday morning. He was arguing very		3	DR. RYAN: It is not necessa
	_		al a	4	them because they are then having rese
	5	strongly that no one ought to be excluded.		5	guidelines that will apply to all free
	6	DR. COOKE: And I am not excluding anyone, Al, that		6	DR. COOKE: That is right an
	7	is exactly it.	and the second se	7	saying.
	8	DR. JONSEN: It sure sounds like it.		8	DR. RYAN: Dr. Seldin.
	9	DR. COOKE: No. That is the point. I am talking		. 9	DR. SELDIN: I think it migh
	10	about research in prisons. I am not talking about research on			
	11	prisoners.		10	the question along somewhat philosophi
	12	, DR. JONSEN: You are excluding anyone who is in prise	on.	.11	we started out by saying that we ought
	13	DR. COOKE: No, from research carried out in prisons.		12	of rights sometime ago, unless it is a
				13	recognized that being in prison, being
	14	DR. JONSEN: It makes no difference. Wherever you		14	is, in a certain sense, a deprivation
	15	put them they are going to be in some kind of a correctional	a de la companya de la	15	wants to dehumanize people more than t
	16	modality.	and the second se	16	be in some ethical way that we say tha
	17	DR. COOKE: No. I can see them in a clinical researc	eh	17	rules, we would then want to allow the
	18	unit at Johns Hopkins Hospital.		18	much right so as not to dehumanize him
•	19	DR. JONSEN: In an unlocked ward without a policeman		19	opportunity and one of the modest litt
	20	out front?			
	21	DR. COOKE: Right. Indianapolis		20	perience is to participate in a resear
fup		DR. JONSEN: Then they are not prisoners.	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	21	I think thus far everyone
Comp	0.2			22	Now, the problem here is the fact that
Reporting Company	23			23	forms of coercion, there may be condit
vers Rej	24 25	they have been before the parole boards and so forth, where	and a second sec	24	sort which prevent the prisoner, in fa
BC	25	they have no incentive to escape essentially because they are		25	rights, that his exercise of his oppor

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are some of the means that ing prisoners.

ary for us to look at earch conducted under the e living individuals. nd that is what we are

ht not be amiss to raise ic ethical lines. Now, t not to deprive people absolutely mandatory. We g confined, incarcerated, of rights. But no one that. The idea would then at given these boundary e prisoner to have as m, so as to afford every tle rights in human exrch setting.

- let me just finish.
t there may be subtle
tions of a detestable
act, from having real
rtunity to be a research

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296 1 subject is, in a sense, a facade. Okay, so what we are doing 2 now, it seems to me, the exercise we are going through, is to 3 specify particularly what minimal conditions might exist in 4 order to insure that the exercise of these rights is not abused. 5 Now, to my mind there are two components to this. 6 It is not merely an accrediting set of standards. We have here 7 review mechanisms which are constantly operative and which 7 8 John tell us, and I can only bow to his wisdom and knowledge 9 in this area, are not unrealistic. There is a lot of turmoil 10 about prison. It is not the case that prisons represent a 10 11 garrison kind of state which is solid and immutable forever. 11 12 The Alabama decisions, the various other things, indicate that 12 13 prisons are in a state of flux and you just heard that there 13 14 may be a major revision in the State of California. 14 15 My own feeling is that if things don't work out along 15 16 the lines that are indicated here, there will be no prison 16 17 research. Fine. Because these are the minimum conditions which .17 18 make it dignified. But I think going through the exercise of 18 19 specifying these conditions is very, very important and I 19 20 personally think the thrust here of setting forth a moratorium 20 21 then specifying the conditions under which research will be 21 22 tolerated, is a very reasonable one. 22 23 DR. RYAN: Mr. Turtle. 23 24 MR. TURTLE: We have heard from the beginning about

this issue of a prisoner's right to participate in research and

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297 1 I think we have become a little bit confused by it. Nobody is talking about affecting a prisoner's right to do anything ex-2 3 cept insofar as he may not have access to a research program in the prison. That is the same thing as if you were throwing a party out in Texas and I had a right to come because you invited me and I didn't have the money to get the airplane to 6 get there.

8 I mean, he is constrained by some other extrinsic 9 mechanism which prevents his participation. It would not be us simply saying you cannot participate because you are a prisoner. We are simply saying that to put it into the prison, put the research project into the prison environment, causes us some problems. Now, we are not depriving him of any rights, any deprivation is a result of his incarceration and not of any decision that this Commission makes. So, I think we really have to, you know, get off this point about what we would be doing to prisoners' rights. DR. SELDIN: If you want to define the state of imprisonment as involving, by definition, no research, that is fine. Now, you are saving that imprisonment, by definition. involves no access to the possibility of being a research subject ---

MR. TURTLE: Access within the prison. DR. SELDIN: Actually, there was some such formulation to say that we reject that yesterday. Nothing happened

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to it. I guess we didn't vote. There was, someone spelled it out. I forgot who did. 2

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DR. RYAN: Pat King wants to respond to that. 3 MS. KING: Mr. Chairman, we took a straw vote. In 4 light of the straw vote, I respectfully request that we go 5 back and agree to do what we were doing. So much of what we Ĉ are now discussing, with all respect to Bob, we hassled out 7 yesterday. We are going to hassle out again when we see the 8 precise wording because if I know this Commission, we will 9 all have eleven different words to offer for the same thing. 10 I suggest that we go on in light of the straw vote 11 and attempt to come to grips with what we are going to do with 12 respect with both setting up standards and conditions that we 13 find minimally acceptable and to doing what the two Bobs have 14 suggested and that is, under what conditions we would allow 15 research on prisoners outside of the prison setting. 16 MR. TURTLE: I would go along with that, although 17 I concur with Bob Cooke in the extreme statement that if we 18 should have research I would be willing to work on it, on the 19

conditions, at least for the purpose of seeing whether anything would happen that would change my mind.

DR. RYAN: Mr. Calhoun.

MR. CALHOUN: I think we have gotten outselves in a bind. We are talking about rights again and rights are relative types of things. I think the problem that we are

1 running into when we talk about this system of standards or 2 principles by which research will be conducted and principles 3 we may, in effect, be denying the rights of prisoners, in a 4 sense, by trying to improve their rights. 5 Because if we make these standards and principles at 6 such a level as I see them going, then research -- and we declare 7 a moratorium -- research is banned. So then, if that happens, and no one can meet those standards that we set here, what 8 9 becomes of the right of the inmate then? In terms of the 10 present situation?

11 MR. TURTLE: What right? 12 MR. CALHOUN: The right that he has now to participate. 13 That he is exercising now. That as the inmates at various 14 places have told us, as Mr. Lawson, who was at a hearing here, 15 and several other people have said, that we want to do it and we enjoy doing it. And that we don't perceive these to be 16 as coercive as, perhaps, you do but we do want that right. 17 18 I think that there may be a subtle sort of coercion unless we 19 are very honest with ourselves in terms of speaking out about 20 it, that we are employing it at this time. DR. RYAN: I want to try and follow Pat's suggestion because I think it is the only way for us to go. I don't think 22 there is any reason for us to try and convince one another. 23 We have really hashed out the prison issue. I would like to 24 call to your attention that the staff did a lot of work in 25

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drafting a report called Biomedical and Behavioral Research in MOdel Prisoners. I presume all the Commission members have 2 read this and I would like for the, and this represents, I 3 believe, a factual description of the kind of contract work 4 which the Commission has worked for. 5

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Now, it is a draft and you can make suggestions, but 6 I think you are going to have to make suggestions on this 7 pretty soon so that we can, in fact, get this out as the back-8 ground material on which we are going to make decisions. I 9 don't want to hear people saying we do or do not know this if, 10 in fact, we have already commissioned information which was 11 supposed to provide us with that if we had only read it. 12 So, that I would like some expression from the Commission as 13 to whether they perceive represents what they asked for, do 14 they have what they need, so that we can go on with the deli-15 berations as Pat has suggested. Karen? 16

DR. LEBACQZ: I was one yesterday who asked to have 17 some time to look at that document. I do have some specific 18 comments on it. But I am not sure procedurally that it is 19 helpful for us to stop where we were going and look at that 20 21 now.

DR. RYAN: No. That is just for your background. 22 DR. LEBACQZ: I hope that we will get to it this 23 afternoon before we close, but I would like to make a proposal 24 for where we are going right now. I would like to know whether ECH. 25

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anyone on the Commission has additional items besides the seven 2 that are before us and all the others that we have thus far 3 talked about as important minimal standards and unless there 4 are other suggestions there, I will make a proposal for 5 standards for research on prisoners outside of prison, so can -6 we please re-direct our attention back to the question of 7 standards and principles.

8 DR. RYAN: There is a motion, actually we have been 9 discussing a motion which was made by Al Jonsen to accept 10 this and it has been seconded. We have been discussing it all 11 this time and all of the comments that people have made have 12 gone on the transcript, such as Bob Cooke's requirement for 13 concordance, Dorothy Height's comment that she wanted ethnic 14 and racial representation, the suggestion of someone that we 15 get objectives as well as the conduct, Joe Brady, and so on. 16 All of those will be incorporated into this, it is my under-17 standing, because they seem to flow naturally. The comparabi-18 lity of remuneration within the setting, some relationship to 19 remuneration outside the setting is going to have to be worked 20 on. We cannot do that here.

But all of those things have been heard. Now the question Karen is asking is, what more do you have to add? David Louisell.

DR. LOUISELL: I have two further thoughts. One concerns the risk factor of the protocol. I am not convinced

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1	that risk should be excluded as a legitimate factor for pur-		l in mining and there are the
2	poses of remuneration. It seems to me that is included in-		in mining coal. What I am saying is
3	evitably when the protocol concerns non-prisoners and I am not		is for inconvenience, not risk, then
4	convinced that it should be excluded where it concerns prisoners		occupations.
5	DR. COOKE: David, the point I was making is that		DR. RYAN: But it isn't, be
6	it should apply to non-prisoners as well as prisoners, that		said, when you go in the submarine se
7	compensation for risk I consider to be bribery and not accep-		than if you are on the surface.
8	table. If you have got to pay \$1000 to get somebody to take		DR. BRADY: Both factors ar
9	some very dangerous drug, I don't believe that kind of research	C	point. You cannot exclude it as a co
10	should be permitted. It seems to me it is the inconvenience and	Y	be the exclusive characteristic for w
11	the time that we ought to compensate people for.	10	
12	In meading that paper on compensation, prostitution,	11	
13	et cetera, the only way I felt that compensation I don't	12	
14	mean compensation, I mean remuneration is acceptable was to	13	
15	take it out of the category of remuneration for risk and have	15	
16	remuneration for inconvenience and time spent. That is what	16	
17	made it no longer prostitution.	17	
18	DR. BRADY: We would never have a bridge built, Bob,	18	
19	if that principle were	19	
20	DR. COOKE: No. The point is that in that essay it	20	
21	was very clear that the reason one pays in research is for the	21	MS. HEIGHT: I will wait.
22	so-called risk. And that is what differentiates it from other	22	
23	hazardous occupations. Participation in research was iden-	23	this. It is an addition to what
24	tified as being different from participation in coal mining	24	DR. RYAN: Add it while you
25	because the purposes were, one, taking risks. The other was	25	DR. LOUISELL: Oh, okay. M

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if the remuneration intent it is like other kinds of

ecause as Joe Brady just ervice you get more money

re involved is David's onsideration. It may not which you are paying. inappropriate to offer

compensation.

l the time at work and I ssay that was submitted to work. I mean, we can argue ot sure it is appropriate. Lease? I think Dorothy

ll, another point but I s over.

point is not germane to

have the floor, David. Ay question is and I am not

1 sure I have come up with a crystallized conclusion yet, but 2 should we add to all our criteria here an explicit one that 3 would defer to local or state law insofar as that law super-4 imposed additional detailed considerations, rather than what 5 we have done? After all, we are an isolated group in a sense, 6 sitting right close to Washington. People on the spot may have 7 additional insights according, particularly, to local condi-8 tions and maybe we should have some covering additional deference.

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9 DR. RYAN: You wouldn't mind if conditions were 10 better, is that it?

11 DR. LOUISELL: We would only say that if there is any 12 additional protection accorded under state law, that we would 13 also pay obeisance to that additional requirement.

DR. RYAN: Thank you. Dorothy Height, please.

15 MS. HEIGHT: I have two points. I had wanted earlief 16 to ask on No. 7, when John Irwin was talking about opportunity 17 for prisoners to organize, was that a specific reference to a 18 particularly type of organization or are we talking about 19 collective bargaining?

20 DR. IRWIN: Again, I feel a conflict of roles because 21 on the one hand I am a person who is involved in trying to get 22 a particular kind of organization into prisons. But in recom-23 mending general principles to the Commission I would not want 24 them to adopt something very narrow in their definition of what an organization was. I think just the right to form organizations 25

and to have some kind of a total say in what kind of organiza-2 tion they want to organize, within limits -- the departments of corrections, of course, are going to insist upon some limits. They are not going to, those which are consistent with their concerns about incarceration.

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6 DR. RYAN: You are talking like student government, 7 | for example, self-governance and discipline, there are certain 8 limits that are placed within institutions, whether it be a school or a prison.

10 MS. HEIGHT: I think in general usage, I would say, 11 the opportunity or the right to organize, for me, speaks a 12 particular way and it might be useful for us to state that 13 when we are talking about prisoner organization. 14 DR. IRWIN: Mr. Chairman, may I comment on that? 15 Just a brief comment to add to Dorothy's concern. 16 DR. RYAN: Could you speak a little louder? 17 DR. IRWIN: Just one comment on that. When we were, 18 in fact, engaged in the series of negotiations, this issue 19 of the nature or what kind of organization came up constantly 20 and their fears were that, in California, particularly, where a series of organizations emerged which they felt were not only 22 bothersome but were dangerous to their operation. We gave them that they had the right to set parameters on what the organization could do and they must have the right, it seems to 25 me, to suspend the operation of the organization and submit

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	1	that to some outside, impartial body for because of the			
	2	operations. All of these things, it seems to me, will natural-			us slip into that. I think when y
	3	ly be developed when the actuality of organizations are emerg-		2	
	4	ing. But there will be special organizations which can be		3	not meant the racial minorities an
	5	contained within the correctional enterprise.		. 4	ethnic minorities and the public,
	6	MR. GRAY: It might be clarifying on that if we		5	saying because the racial and e
	7	specified, I think this is Dorothy's concern, if we specified		6	of the public.
	8	the purpose or organizing rather than the from of the organiza-		7	DR. IRWIN: Well, what a
	9	tion. I have the right to organize a softball team but that		8	MS. HEIGHT: That would
	10	isn't what we are talking about.		9	public something of that sort.
	11	DR. RYAN: If you want to be more specific, it is		10	DR. RYAN: Dr. Brady.
	12	for governance and self-discipline.		11	DR. BRADY: To the motion
	13	MS. HEIGHT: Something of that sort because other-		12	protestations on several occasions
	14	wise, I think, I mean we have to face the political realities		13	not personally persuaded that these
	15	and I think that this, to me, when I ask for the right to		14	developed in a workable way and add
	16	organize, I am talking about collective bargaining. I think	÷.,	15	setting. Secondly, I find myself
	17	that is what would be generally indicated. I think our chances		16	the continuum to the two Bobs. I a
	18	of even having people discuss what we are talking about are		17	to the right or to the left. I am
	19	limited if it is seemingly too weighted in one direction.	-	18	I am prepared to vote for a morator
	20	The other point that I want to make is just an aside		ען	the logic of the situation says to
				20	motion and look at these criteria,
- È	21	and that is, even in our language as we say it, we have been		21	torium let me at least explore the
Compa	22	a little inclined to say that we would have racial and ethnic		22	anybody is in compliance or can be
Reporting Company	23	diversity and the public. I think that is the heart of the		23	MR. TURTLE: How long would
BOWRIS Rel	24	whole minority conference. The public is made up of racial	and the second sec	24	DR. BRADY: Well, I don't
80	25	groups, ethnic, different ethnic groups. I would hate to have		25	MR. TURTLE: That is exac

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you say the public, this is In the country. The public has and so if you say racial, you have to find some way of ethnic minorities are part

bout and other public? be good, yes. And other

on. Despite Lee Calhoun's a, I am not convinced, I am be guidelines cannot be thered to within some prison almost at the other end of am not sure whether that is not at all convinced that rium until -- in other words me that if we vote this that before I vote a morasituation as to whether in compliance with these. d that take ycu, Joe? t know.

ctly why Bob and I go to

1 the other approach.

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	1	the other approach.		1	rei
	2	DR. BRADY: We are arguing that we don't have the	•	2	th
	3	facts so that we cannot do anything, okay. I have some reason		3	-
	4	to believe that at least in some limited institutions there		and the second se	to
	5	may well be an approximation to this. In any event, I am not		4	fo
		persuaded that this is an impossible set of requirements and		5	da
	7	I think there may even be an institution that will come into		6	of
•	8	compliance very quickly and even if there was one, it seems to		7	I
	9	me we have made an advance in this regard.		8	-
	10	So, that is why I am not prepared to vote for mora-		9	su
				10	wh
	11	torium.		11	in
	12	MR. TURTLE: Could I ask a question?		12	su
-	13	DR. RYAN: Yes.	1	13	th
1	14	MR. TURTLE: When you say even if there was ore, we		14	ha
1	15	would have made an advance.		15	me
	16	DR. BRADY: With the seven model.		16	th
	17	MR. TURTLE: Well, if there is one institution which		17	da
	18	exists, what have we done, you know, to advance anything by		18	CO
	19	allowing research to be done? We have identified it as meet-		19	qu
:	20	ing our standards.	a Generation of Second	20	
	21	DR. BRADY: We have increased the level of conscious	a viena des seta los seres	21	te
thout the	22	ness.	a state of the sta	22	wa
100 Gu	23	DR. RYAN: Pat King, please.		23	wa
Bowers Reporting Compony	24	MS. KING: Yesterday in the report on the survey of			·
BOWERS	25	priscns there were some suggestions made about inadequate		24	ti
				25	sa

emember Don Seldin said we should consider writing some of nese standards in two ways, first, those that apply overall o the prison and some standards that we find are necessary or the research setting itself. There were some things yesteray in that report, for example, the language, the difficulty f language used in consent forms in prison, for example, that think should be incorporated in terms of standards too. I am not trying now to be exhaustive. I am just uggesting that we go through and cull from those documents here we have had factual data some of the suggestions or nadequacies, to have them pointed up. I also would like to uggest that we go back and discuss the remuneration issue and he reason I would like to suggest that is if I were the staff aving to draft a recommendation on that, I, for the life of e, haven't heard anything that this Commission has said yet hat would give them any guidance on what the final recommenation should look like. Even the question of the term of omparability between, you know, jobs leaves itself unanswered uestions and perhaps we could try to do a little bit better. I don't have any suggestions right now, I can still ell you that it is a hole in giving them some guidance. Mike ants to respond to that. MR. YESLEY: Well, I just want to say on the remunera-

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MR. YESLEY: Well, I just want to say on the remuneration issue that I think that some general language might be satisfactory to all, language to the effect the remuneration

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generally be comparable to what is otherwise available in pri-2 son industries and, secondly, that it generally comparable to 3 what might be necessary to attract outside volunteers in a free 4 environment.

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5 MS. KING: My problem, and I thought that was about 6 as far as we had gotten, my problem with that is that every-7 thing we do know suggests to us that to say that is almost to 8 say nothing, that we should go a little further and to try and 9 figure out if there is any feasible means of being more specific 10 in that area. Not detailed, but a little more specific.

11 DR. RYAN: Well, that is identified as a problem. I want to call on the others who have their hands up. Al 12 13 Jonsen first.

14 DR. JONSEN: I would like to speak to the moratorium 15 issue. I conceive of the problem, conceive of our work proceed-16 ing in this way, that we set these standards and we ask for 17 a prior approval in accord with these determined standards. 18 In other words, we are not saying that ongoing programs will 19 be reviewed in accordance with these standards but we are, 20 rather, saying that there will be a willingness on the part of 21 the accrediting body to entertain evidence that an institution 22 is in compliance.

23 I think that, in effect, is a moratorium, although 24 conceivably an institution could come tomorrow and say, we are 25 in compliance. But it seems to me that Joe's remark about the

size of the problem is opposite. It might only be one institution in the United States. At most, we have got a list of 2 16 institutions that were presented by the drug company, there 3 4 are probably a few more.

5 DR. RYAN: That is the whole point. There aren't that 6 many institutions involved.

7 DR. JONSEN: I would like to suggest that the more 8 we think of this in terms of reforming the entire prison system in the United States, the more absurd it becomes. We are 9 10 really talking about can any single institution meet standards 11 that we are setting down?

12 DR. RYAN: David Louisell, please. DR. LOUISELL: In response to the moratorium, can't we for the present agree that it is a separate issue, that we don't need to face up to it right now and our attitude on whether to make it explicit ultimately may be dependent upon satisfaction with these criteria? So, we don't need to get bogged down with the moratorium now, I don't think. DR. RYAN: Eliot Stellar.

20 DR. STELLAR: Could I ask the Commissioners whether 21 we are discussing therapeutic as well as non-therapeutic 22 research? Bob made this distinction earlier in our interchange. 23 It seems to me there are some differences and I would like to 24 hear our views on them, particularly in research directed toward 25 rehabilitation, the behavioral research, but perhaps other

therapeutic research.

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2 MS. KING: Can we hold the behavioral? Hold the
3 behavioral for a minute and --

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DR. RYAN: I had thought about that. Pat had asked
us to keep in the back of our mind that we might keep them
separate and when Bob Cooke said research that could not be
conducted on any other subjects, he was referring largely to
biomedical research. If you start talking about research in
the rehabilitation system, the penal system, into recidivism
or other kinds of activities, you are talking about something
that is specific for the prisons.

And, in point of fact, none of the things that are 12 wrong with prisons are ever going to be improved unless one 13 uses some kind of research model to try new methods and see if 14 they work. On the other hand, I feel very strongly that if 15 the quality of prison life is so bad that you wouldn't allow 16 biomedical research to go on, that you certainly would place 17 the prisoners in even greater jeopardy to have research going 18 on with respect to their lives and so on and so forth, that 19 was in an environment that was that poorly controlled. 20

So that in the hope to come to some minimal standards of biomedical research, having a prison organization that would have responsibility for the objectives, conduct and kinds of research done in their institution along behavioral lines, as Joe Brady has talked about and is in the staff report, I

would not be concerned. It is only if we lower our sights, if 2 you will, that then we would have to specifically go down the 3 line and say that we mean only biomedical research and not behavioral research. That is how I have interpreted it. 5 There are other people that want to speak and I think it was Don Seldin first, and then Karen. 6 7 DR. SELDIN: Two quick points. One is if the ιff 8 should re-draft this thing in a formal way, I would like to 9 suggest once again that there be two separate categories of 10 recommendations, one concerning prisons in general, the minimum 11 conditions, and the other concerning the research aspect busi-12 ness. That is not a big deal but I do think that should be 13 highlighted and make things more unambiguous. 14 The second point is that there was an addition to 15 item 7 which was drafted and handed to Michael. I don't recall if that was read to the Commission or whether it needs to be 16 read but it is available and it answers one of Karen's points, 17 18 is there anything in addition? I do think that the establish-19 ment of a redress and grievance board independent of the IRB 20 and the accrediting group is necssary and that has been added. 21 Now, whether you need to read it, I don't know. 22 DR. RYAN: Karen next, please. 23 DR. LEBACQZ: This is another very specific matter. 24 I don't know what the situation is in Michigan or some of the 25 other places that we have not looked at, but I do know that in

	1	314 California there is a phenomenal movement of prisoners from one	and the full state of the state of the	
	2	institution to another, so that prisoners are in point of fact	and the second se	The other thing that I don't th
	3	being transferred and can request to be transferred in a system	2	moment is the Commission's desire with re
	4	within the State. Therefore, if we are going to talk about	3	dance that I think you have said before i
	5	equal opportunity to participate in research, we are going to	4	Commission expects to be in the staff doc
	6	have to impact on more than just those 16 individual institu-	5	what uncertain about the Commission's over
	7	tions in which research might be done, because we are also	6	that.
	8	going to be saying something that has implications for the	7	DR. RYAN: I think the last poi
	9	movement of prisoners from one institution to another.	8	staff did include in the document you pre
	10	I think it is very important that we acknowledge that		of the concordance phenomena. One with r
	11	recognize it and get it before us. Equal opportunity to par-	10	of projects or risk-taking that would be
	12	ticipate will also, of course, have ramifications for the fact	11	versus outside, another with the actual of
	13	that most research is done in prisons which are populated by	12	the same kind of research, participating
	14	males and not by females and there may be some ramification in		research protocol inside and outside, and
	15	that direction as well.	14	the Commission has any unanimity on that
	16	DR. RYAN: Brad, please.	15	that we put those alternatives down in ou
	17	MR. GRAY: Two points that I think perhaps the .	10	those that have to go into our final docu vote them up or down. I don't see any
	18	desires of the Commission are not entirely clear to the staff	17	
	19	or at least to me. One is the extent to which the conditions	18 19	have been joined. MR. GRAY: That is what I sense
	20	that are being set forth, under which biomedical research can	20	if the expectation was that the staff was
	21	be done, would also apply to research which involves inter-	21	saw as non-resolution within the Commiss:
Company	22	views, questionnaires and that sort of thing, and does the	22	DR. RYAN: I doubt it. I think
Reporting Co	23	Commission intend that the only prisoners who can receive a	23	is I doubt the Commission, they can advis
ers	24	questionnaire are those which are in prisons that have been	24	is incorrect, would allow very high risk
Bott	25	accredited and so forth, maybe I shouldn't use that word.	25	just because it is a prison. That is fur
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think is clear at the regard to this concore is something that the document and I am someoverall feeling about

point, of course, the prepared three aspects h respect to the kinds be allowed in prison l offering and taking of and I don't sense that at point. I would suggest our deliberations and locument, we are going to r -- I mean, the issues

ensed. I didn't know was to resolve what I ssion.

hink the extreme of that lvise me if my perception lsk to go on in prison further demeaning of the

316 quality of life or the perception of the quality of life of the people within it. How far that goes down the road, whether 2 2 it goes to equal opportunity outside plus counting the numbers 3 3 that participate may show that they are equivalent, as Bob 4 4 at one time suggested, I don't know whether we would all agree 5 5 6 to that. Barbara. 6 MS. MISHKIN: Yes, I just wanted to indicate the 7 7 reason you have three different things there, with an "or" 8 8 between the second and the third, is that from the last trans-9 9 cript it was entirely unclear which of the -- there are three 10 10 gradations in the concordance principle -- it was very unclear 11 11 to the staff which, if any, would be supported by the Commission. 12 12 DR. BRADY: What page are you on? 13 13 MS. MISHKIN: On page 80 of the staff paper here, 14 14 D1, A, B, and C are three different variations, all of which 15 15 were suggested in the meeting and there was no resolution. 16 16 DR. RYAN: I think with respect to your first ques-17 17 tion, Brad, that isn't clarified. That is the questionnaire. 18 18 We don't know to what extent they are being allowed in prisons 19 19 at the present time. I think one of the things that we focused 20 20 on largely has been biomedical research, FDA Phase I drug 21 21 testing, because it is the most visible. When, in point of 22 22 fact, we have looked for behavioral research, we cannot find 23 23 any and no one would suggest, necessarily, that the questionnal res 24 24 -- some people would maintain they are not really research. 25

But I would like to point out that somewhere along the line the Commission should, with respect to prisons as well as to other kinds of research that we make pronouncements on, come to grips with the fact that research can be conducted to evaluate ongoing therapy, ongoing behavior, or just research to see whether or not the prison is a good place to live. We have to build into our thinking and the thinking of the public that that kind of research is mandatory, that it is an essential ingredient of therapy, that is, monitoring the quality of therapy, that it should be structured as research if it is going to be valid and the kinds of requirements that we would make for that might very well be different. We might say, look, if you want to evaluate what you are doing in a prison now and you are not going to change anything, then the kind of requirements you would have for doing that research might be different than one in which you are going to manipulate people. MS. KING: I want to say in fairness to -- it may not be what Brad had in mind, but it is something I think we should keep in mind. You know, there is a lot of research done in prisons on X, YY, whatever you call it, syndrome, or whatever, in an attempt to determine -- and this is on the borderline -in an attempt to determine the presence of whatever they are, chromosomes, in prisoners. Ken, I could see, and I think this is what Brad has raised or perhaps getting to, I can see a 25

connection with that type of research, not only the physical and how you determine about genes and stuff, but that you would 2 want to do, for example, background and survey information 3 and demographic, and obtain demographic material, that would 4 go along with what you are talking about in the biomedical as-5 pects of it. So, I understood the point he is making. I also 6 understand that we have got to deal with that. 7

But we also have to understand that there are some 8 things that are not drug research that go on in prisons and 9 we have got to meet the question of whether they can only go 10 on like an X, YY protocol --11

DR. RYAN: I am glad you brought that up because, in 12 point of fact, everyone was saying that research is not done 13 in European countries. To my way of thinking, all of that 14 X, YY originally came out of European countries and as I under-15 stand it, there was no informed consent and none of the things 16 that we are worried about and perhaps there were none of those 17 things and that is an even more subtle kind of control of 18 people's lives. 19

Perhaps, because they don't have other kinds of 20 research, they haven't even wondered or worried about the safe-21 guards for those prisons. But I think we should get a report 22 on that. No, I am really quite serious because that goes to 23 the heart of behavior, social stigmatization and everything 24 else that people have been concerned about with prisons. In 25

point of fact, most of that research was done outside the United States without the kinds of safeguards that we are worried about for a much less risky kind of research procedure. I think, I really think it is terribly important, Pat. Bob Turtle.

MR. TURTLE: In view of Pat's proposal and recognizing 6 Joe Brady's reservations, I would like to move an amendment to the document that is presently on the floor, which would strike out "may" in the first sentence and insert "should not." And strike out the "why that (?) " in the second line and substitute 10 "unless, " so the document would begin, the Commission recommends the Secretary of DHEW should not conduct, support or approve biomedical or behavioral research involving prisoners unless, and then proceed.

DR. RYAN: Okay. Now, with those changes, you would vote for this document?

MR. TURTLE: I am not sure but I would --(Laughter.)

No, but I think the point is that --DR. RYAN: Well, don't go down the road and make changes like that and then say, well, I don't like it. MR. TURTLE: I gathered that this is basically what Pat was saying. I am concerned about what Joe is saying. I quess my feeling is that I would not want to work on these conditions at any great length if it was not going to be clear

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that there would be a requirement that the conditions must be met before the research could go on. 2 DR. RYAN: I would agree with that. I am just teas-3 ing you a little, Bob. I wouldn't want to work on these 4 things, either, unless we are going to do something on it. 5 MR. TURTLE: Basically I would say that I could not 6 vote for any situation in which the current situation was 7 allowed to continue without a prior review and the burden being 8 on establishing that the conditions had been met. That is why 9 1 moved this, to find out if we really are all there in view 10 of Joe's concern about it. 11 DR. RYAN: I am going to break for lunch in just a 12 minute. Al Jonsen wants to speak. 13 MR. TURTLE: We don't have a second on the amendment 14 DR. JONSEN: I will second it. 15 DR. RYAN: Do you want to discuss the amendment? 16 MS. KING: I want to ask him and we can do this 17 after lunch, to have us discuss the propriety of taking a vote 18 at this time, as being more than a straw vote. I think that 19 we should discuss that before we actually vote on the motion. 20 DR. RYAN: Well, we, you know, one of the alternatives 21 is to table it until the report comes back and then you can 22 make a formal vote, if that is what you want to do. Al Jonsen. 23 DR. JONSEN: With regard to appointed breadmade (?) 24 24 that may have some bearing on the way in which this is worded, õ 25 \$ 25

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we may not want to be as strict about certain kinds of research, 2 namely, making clear that therapeutic research may, in fact, З take place in settings where the institution has not met all these standards. That is a possibility. 5 Also, just a second, Don, it is a possibility but 6 also, other kinds of evaluation research of the sociological 7 type, we may permit in a wide variety of institutions, many of 8 which would be far below these standards, precisely for the 9 reasons that the Chairman mentioned, that that might be impor-10 tant research towards changes in the prison system and things 11 of that sort. So, it seems to me that we ought to at least 12 take into consideration that this primarily applies to the non-13 therapeutic and that we might want to set certain other kinds 14 of standards. For example, I imagine that one of the, that 15 two of the problems that might accompany all sociological 16 research in any institution, in any prison, would be the con-17 fidentiality question and the clarity about objectives of the 18 research which some prisoners might not want to participate in 19 DR. RYAN: I think what I said before, I think the 20 evaluative research is all right but when you are worried about 21 confidentiality and coercion, what good is the research if 22 it is conducted, even if it is a questionnaire? 23 DR. COOKE: It is evaluative research. I want to study the quality of health care in various kinds of prisons. DR. RYAN: Well, that is separate.

DR. COOKE: I mean, you have to have bad ones as well as good ones or it is meaningless kind of exercise.

3 DR. RYAN: Right. That is why we should short those
4 out. Lee wanted to speak and then I do want to break for
5 lunch.

6 MR. CALHOUN: This is my final observation. I have 7 looked at these proposed principles and standards and I thought 8 about research conducted in the so-called free world environ-9 ment and I thought about the fact that if I were a poor black person in the ghetto, I could probably go out and get myself 10 involved in research project with these standards coming Lowhere 11 near, the possibility of my getting these standards to apply 12 is out of this world. I would certainly not have an adequate 13 range of opportunities for employment, education, occupational 14 15 training, leisure and cultural activities, and yet we are going to apply these standards to persons who come from that 16 sort of environment oftentimes and I question whether that is 17 realistic in the sense that we may deny them certain oppor-18 19 tunities and if you go down this whole range of standards, I think that it becomes more and more an elitist type of docu-20 ment that may have very, very few implications for reality in 21 terms of posing certain standards that don't apply. 22

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I will leave it at that.

MS. KING: Initially in this discussion on prisons 25 I think we should all keep in mind at least certain of us

recognized that in the free world there are all forms of 1 2 coercion, there are all kinds of reasons why people sell their bodies, their blood, almost their souls to keep body and soul 3 together and that if we were to focus only on the coercion that 4 5 existed in the world we would get nowhere, that what we were trying to recognize was a situation that we were asked to deal 6 with and perhaps our deliberations, in the deliberations, 7 Michael, in terms of the staff paper, perhaps there should be 8 9 some explicit recognition of the fact that we do appreciate that coercive factors exist in the free world but we were asked 10 to focus on a particular setting to see if that setting would 11 12 permit research.

I think to say that the world is bad is not an excuse not to make the prisons a little bit better. Maybe the next commission will tackle the world. It is unreal to do the opposite of what Lee suggests because we cannot do anything about the world, not to do anything about a prison. MR. CALHOUN: No, no. I have an alternative. What I am suggesting is that if, you know, if one has certain standards, wants to adopt, you know -- you have a choice here. If you are going to have these types of standards, then what population would it realistically apply to and who can realistically come under these types of standards? DR. SELDIN: Prisoners.

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MR. CALHOUN: No, I am suggesting something entirely

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1	different.		1	AFTERNOON SESSION
2	DR. RYAN: 1 am suggesting that we break for lunch,		2	DR. RYAN: I wonder if we co
3	hear me out, that we re-convene at 1:30. I believe the		3	Coffee will be available until 3 o'clo
4	Clinical Center is open if you don't want to rush. We are		4	to break for coffee. Anyone who wants
5	going to start at 1:30. We are going to finish at 3:00.		5	it, however. I think I would like to
6	(Thereupon, at 12:08 o'clock p.m., the meeting was		6	
7	recessed until 1:30 o'clock p.m., the same day.)		7	as we go along to help us.
8			8	Mike, why don't you just tac
9			9	in April for the public hearings?
10			10	MR. YESLEY: Okay. We have
11			11	Federal Register. I guess maybe that
12			12	We have given notice in the federal re
13			13	
14			14	research subjects, and the use of the
15			15	
16			16	notice in the Federal Register we sent
17			17	copies of the notice to particular org
18			18	be interested, and of course, the ones
.19			19	response to the notice we have request
20			20	or organizations to speak on the issue
21	\mathbf{r}_{i} and \mathbf{r}		20	as research subjects and another 15 in
tr 22			<u>}</u>	organizations to speak on the use of t
22 23 23 23 23 24 25 25			22	mentally infirm, for a total of 38 pre
utroday 24			23	Now, this obviously presents
sia.mog 25			24	what we had anticipated for the next m
			\$ 25	WHAT WE HAU ANTICIPALED IOT THE MEXT N

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1:37 P.M.

ould reconvene, please? ock. We are not going s to may go out and get

break our train of ms of business if we may

ckle what we have to do

a advertised in the is not advertising. register of a hearing use of children as institutionalized In addition to giving at out a few hundred reganizations that might es in the media. In sts from 23 individuals he of the use of children individuals or

the institutionalized esentations.

s problems because meeting was a two-day

326 meeting on Friday and Saturday with Friday being given over to the hearing and Saturday for business, and this business 2 would include, of course, a return to the prison issue 3 with a discussion of the draft report that the staff will 4 prepare and also your initial deliberations on the use of 5 those two categories of subjects. So, there is some business, 6 and also the special study people will be coming in at that 7 meeting. So, I think that you need a full day for 8 Commission business, and you may need most of the day for the Ŷ hearing. 10 Now, there are some alternatives which I will 11 present to you and see which way you want to go. First of 12 all, there is the question do you want to hear all 38 people? 13 I would estimate that you can hear 24 in a day if you give 14 them each 10 minutes, plus not more than five minutes of 15 questions. If you do want to hear all 38 people do you want 16 to cut down their presentation time to five minutes each, 17 and that way you can still get through in one day? 18 Another way to get through in one day would be 19 to hold simultaneous hearings on the Friday, one on the 20

to hold simultaneous hearings on the Filday, one of the institutionalized mentally infirm and the other on children. All of these are possibilities, and finally the final alternative which may be the most likely is to schedule an additional day, perhaps the Thursday to commence the hearings, have them run through Friday and then have the regular

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meeting on Saturday or possibly start on Friday and go through Sunday. 2 DR. RYAN: Public hearings are not necessarily 3 Commission business meetings. á 5 MR. YESLEY: That is right. So, they don't require a forum. 6 DR. RYAN: But we would like as many Commission 7 members to be present given that range of alternatives. 8 We need some guidance. Pat? 9 MS. KING: I would really prefer to structure 10 it by doing mentally incompetent persons on one day of 11 hearings, children the second day of hearings and the 12 third day a business meeting. I think if we are not going 13 to meet tomorrow which took away the having to do double 14 three-day meetings that a three-day meeting in April might 15 be manageable if we all had enough advance notice, but 16 Sunday, not Thursday. 17 DR. STELLAR: Sunday, absolutely. 18 MS. KING: Sunday, not Thursday because you are 19 back into all our schedules which we did not block off 20 before. 21 DR. RYAN: That would mean then that there would be 22 a public hearing on all day Friday. It would be half a day 23 of public hearings on Saturday. Saturday afternoon would 24 be a business meeting and all day Sunday would be a business a 25

meeting.

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MS. KING: Or we might even be able to finish if we do the half day, if we don't talk so much which this Commission likes to do, if we don't talk so much during the hearings and can get some business done Saturday afternoon. Maybe it would mean that we would be really needing Sunday morning with just a full day of business meeting.

MR. YESLEY: If you did that on Friday you would 8 have the institutionalized mentally infirm, because that is Q 23, and that will take a full day, and that is a question of 10 how long the 15 -- I am sorry, the 23 children would be 11 on Friday, and the other would be 15 on Saturday morning, 12 and it is a question of whether it would take the whole 13 morning or less, but as soon as the hearing ended we could 14 go into the meeting. 15

MR. TURTLE: Is there any problem with having the 16 hearings run into the evening starting them either Thursday 17 evening or letting them run Friday? 18

MR. YESLEY: There is not a problem except as to 19 your endurance. 20

DR. SELDIN: Why don't we say, Friday, Saturday 21 and Sunday, and hopefully we can get through Sunday at 22 noon? 23

DR. RYAN: I think that if we are going to be here 24 on Sunday please count on a day of that Sunday, please. \$ 25

DR. STELLAR: Is it Easter Sunday? 1 DR. BRADY: No, it is Mother's day. DR. RYAN: What are the dates? 3 MR. YESLEY: It is the 9th, 10th and 11th. DR. RYAN: Karen, please? 5 DR. LEBACQZ: Just a question on the limitation 6 of speakers. I am still a little bit concerned about whether 7 we can really hear 23 speakers in one day and do any justice 8 to their views, also whether we would, indeed, restrict the 9 speakers on Saturday to a similar length or if one wants to 10 call it, shortness of time so as to get through with the 11 hearings, not to spend the entire day on Saturday on hearings, 12 but perhaps the morning or morning until 2 p.m. 13 DR. RYAN: We could do it with 10 minutes for them. 14 That is what we have done with the other public hearings. 15 Each one will be invited to present something in writing 16 which they have to do in order to come to the public hearings. 17 This will give you the flavor of public input. It won't 18 allow you to have a prolonged dialogue with each individual, 19 but if you want more time the Commission can structure 20 another day of meetings or of hearings at which perhaps 21 fewer might --22

MS. KING: The proposal then is what, 10 minutes of presentation and how much of questioning? MR. YESLEY: Five minutes.

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MS. KING: Why don't we do just the opposite? Why don't we ask each public speaker to present us with 2 a written thing which they always do anyway and come for 3 oral delivery, not to read what they have written for us but A to read a summary of the high points, the critical points 5 that they think that they would want to focus our attention 6 on and let us ask some questions for 10 minutes. Quite 7 frankly, I found the questions more valuable than anything 8 because I can go back and read the speech. So, I would Ŷ reverse the timing and ask that they summarize what they 10 have said in five minutes and then let us question for 10 11 minutes. 12

MR. YESLEY: If I could just make a suggestion, I 13 have a different perception. People will be traveling a long distance, and at least, I think in their minds the thought of coming to make a presentation in five minutes, 16 they might feel that they were not being given adequate opportunity to express their views. 18

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DR. COOKE: The last time we did it, you remember 19 some of the speakers really only spoke for a couple of minutes, 20 and the time was not too badly handled. 21

MS. KING: Can't we do it this way? If you are 22 worried about people's perceptions, can't we send a notice 23 to them, giving them 10 minutes but suggesting that the 24 greatest value to everybody would be in the increased 25

1 interaction between the two, and we feel further --2 DR. RYAN: We are going to allow them 15 minutes. 3 DR. STELLAR: Why don't you tell them that. 4 DR. RYAN: They must keep their remarks under 5 10 minutes, and if they can keep them to five it will allow 6 a more meaningful interchange for the Commission. So, they are traveling a long distance to spend 15 minutes, not five. 7 8 Karen, did you have anything to add? I think if 9 that is settled we should go on to the next item on the 10 agenda, and that I would like to -- it is not clear in the 11 agenda, and that is the Congressman Quie, Mrs. Kaysac's 12 letter, your concern, Bob, the question of what we do about behavioral research in the educational system. 13 My suggestion and the suggestion that has been 14 made to me by Charles Lowe is that we give the staff the 15 opportunity to try to select someone who could come on for 16 a short period of time and develop the information, the 17 fundamental information that we need to identify the kinds of 18 research that are going on and what the nature of the problems 19 are, and then to go from there, because at the present time 20 we cannot even talk about getting information. We don't 21 know what sorts of information we need, what is going on out 22 there. So, the staff is prepared to try and seek someone, 23 perhaps on a short-term basis to look into the issues that 24 were raised in that correspondence about behavior modfication, \$ 25

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	1	experimentation in the educational system.	1	constrains action at the moment is the
	2	DR. BRADY: Do you have some candidates for that job?	2	develop detailed background information
	3	DR. RYAN: NO.	3	
	4	MR. YESLEY: Basically what we would like is sort		
	5	of an instruction to develop information either by adding		
	6	someone to the staff on a temporary basis, conceivably by	6	
	7	short-term contract	7	obviously.
	8	MS. KING: So move.	8	MR. TURTLE: Quie asked us wh
	9	DR. BRADY: Second.	9	I was not sure that he was asking the d
	10	DR. RYAN: Is there further discussion?	10	DR. RYAN: In any case the fe
	11	It there is none, all those in favor?]]	various Commission members is that we w
	12	(There was a chorus of ayes.)	12	MR. TURTLE: I think we ought
	13	DR. COOKE: Then do we reply back to the General	13	to the congressman so that it makes som
	14	Accounting Office?] 4	just a freudian slip by Charles that is
	15	DR. RYAN: Charles' letter to Congressman Quie	15	so it ought to be corrected.
	16	says that we are going to take it up at this meeting.	16	I have the impression that th
	17	DR. COOKE: So, now we are going to tell them that	17	asking us for our position on the matte
	18	we are going to tackle the problem.	18	1
	19	DR. RYAN: We are going to tell them that this is	19	MS. KING: I agree with Bob T
	20	the way we are going to proceed. We are going to try and	20	unfortunate choice of terms.
	21	identify it and see at what level we can, yes.	21	DR. COOKE: Our position is w
i Logen	22	MR. TURTLE: What is the department's position	^b g 22	at it.
- Central Landaria		have to do with all of this, and what department is Charles	و 23	DR. RYAN: As a matter of fac
		referring to in his letter?	11.0da 24	now, what he is talking about or what h
BCW01	25	MR. YESLEY: Charles' letter of March 4 is what	25	what constrains action is the obvious n

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what we thought about it. department for anything. feedback I get from want to look at it. Tht to correct the letter some sense. If this is is one thing, but even

the congressman is ter. If I am wrong

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we are going to look

act, as I look at that he should be saying is need to develop

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	1	detailed background information.		
	2	MS. KING: The department's position. That is an	· · · · ·	we can take up the Belmont document and
	3	unfortunate choice of words.	2	time in April to do so, that changes, su
	4	MR. YESLEY: Delete the next four or five words.	3	so that it conforms with the Commission
	5	MS. KING: Yes.	4	addressed.
	6	DR. RYAN: Let us not get embroiled with that.	5	DR. BRADY: You are talking at
	7	We know what we are about. We have been asked		section reports that have been circulate
	8	MR. TURTLE: I wonder sometimes.	7	DR. RYAN: Ethical principles.
	9	DR. BRADY: You know what Charlie's posture is	8	ultimately is going to be the Commission
	10	on what this Commission is.	10	is true for the Bob Levine papers. He have
	11	DR. RYAN: No, I won't accept that.	11	go over in detail. I don't know how man
	12	MR. TURTLE: I won't either.	12	have read it as yet. The staff could be
	13	DR. RYAN: I will set the record straight, Bob.	13.	that into account because the selection
	14	Does this meet the intent of your letter so that we are	14	to have to be a major part of the Commis
	15	going to go ahead and do that?	1.5	with the others.
	16	DR. BRADY: I will provide you with some sources	16	DR. SELDIN: I certainly would
	17	for recruitment, Michael, at least places you can look around.	17	papers be taken into account in the prep
	18	DR. RYAN: 1 think other people who have thoughts	18	DR. RYAN: Okay. Bob Levine,
	19	on this should also help us.	19	DR. LEVINE: I would like to r
	20	I think the next thing I would like to point out is	20	that paper and that is that before it g
ii Vi	21	that you have some papers in your books. You have the	21	any sorts of things that the staff migh
		discussion of the draft of that Belmont report. We cannot	22	on the overall as there is a developing
Donother	23 24	discuss that in detail now. I think that what we should do is for Commission members to read this, to make their	23	of the other specific charges to the Co
ruon D	24 25	specific suggestions, feed them into the staff so that when	24	some things in there that have not been
Ĩ	A. 4	apacted sayyou and, here then they the built be that when	25	by the Commission, some of which as far

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nd I hope we will have suggestions and so on on's desires can be

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about the individual ted.

es. I mean what on's report. The same has one paper here, we not had a chance to many Commission members be instructed to take on of subjects is going mission report, along

ald suggest that the reparation.

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o make one comment on gets incorporated in ght want to synthesize ng synthesis on some Commission. There are en discussed at all ar as I know, some of the procedures for selection of subjects, such as the development of community consent and so on has not had any discussion. I don't know the extent to which the Commission might want to use some of these things or reject some of these concepts and consider alternatives. It may be quite difficult for the staff to work them into any documents it is developing until they hear the reactions to them.

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B DR. RYAN: Whatever they will do will be in draft form, Bob, and I think your concept of community participation with respect to selection is not too far into the kind of self-governance you were talking about within prisons or the objectives in conduct of research and who gets chosen and so on, so that we may very well develop some thinking about that as we go along.

There is one thing that Pat King had been concerned 15 about and that is under Tab 5, I believe, and that is the 16 application of any principles we develop to protect human 17 subjects of research, the extent to which such guidelines 18 or other appropriately developed guidelines could be used for 19 the protection of individuals receiving health care services 20 under the aegis of the Secretary of HEW. The staff has 21 suggested starting at this by developing a staff paper and 22 getting a colloquium of consultants as a first step, to get 23 the background information. 24

MR YESLEY: I might say that Dr. Lowe, if he were

here would express the suggestion that the Commission review the staff paper and then determine whether or not the colloquium should be held. However, we would, in advance, set up the colloquium tentatively.

5 MS. KING: It sounds like a very good idea. I am 6 always willing to wait just to see if I might be wrong, but I am definitely in favor, at this stage, even, of having 7 a colloquium of experts for several reasons which do no 8 9 go to the concerns that perhaps Dr. Lowe is talking about. 10 One, at some point I want to have an interaction again from 11: representatives of minority community, not at a minority 12 conference. It would be a very appropriate mechanism to 13 again allow some of the participants in the conference who are also experts to participate at this stage in the health care area. So, I think a colloquium may be needed because 15 of that aspect of it even though staff paper may be adequate 16 17 in some sense and may be very good in some other sense. 18 It is, again, a chance of input in an area which is of 19 acute concern.

It sounds good, Mike.
DR. RYAN: Mr. Calhoun?
MR. CALHOUN: Yes, I think the staff paper on the
colloquium serves different functions. The staff paper
as was envisioned in staff anyway was to give some
identification of the types of programs that are under the

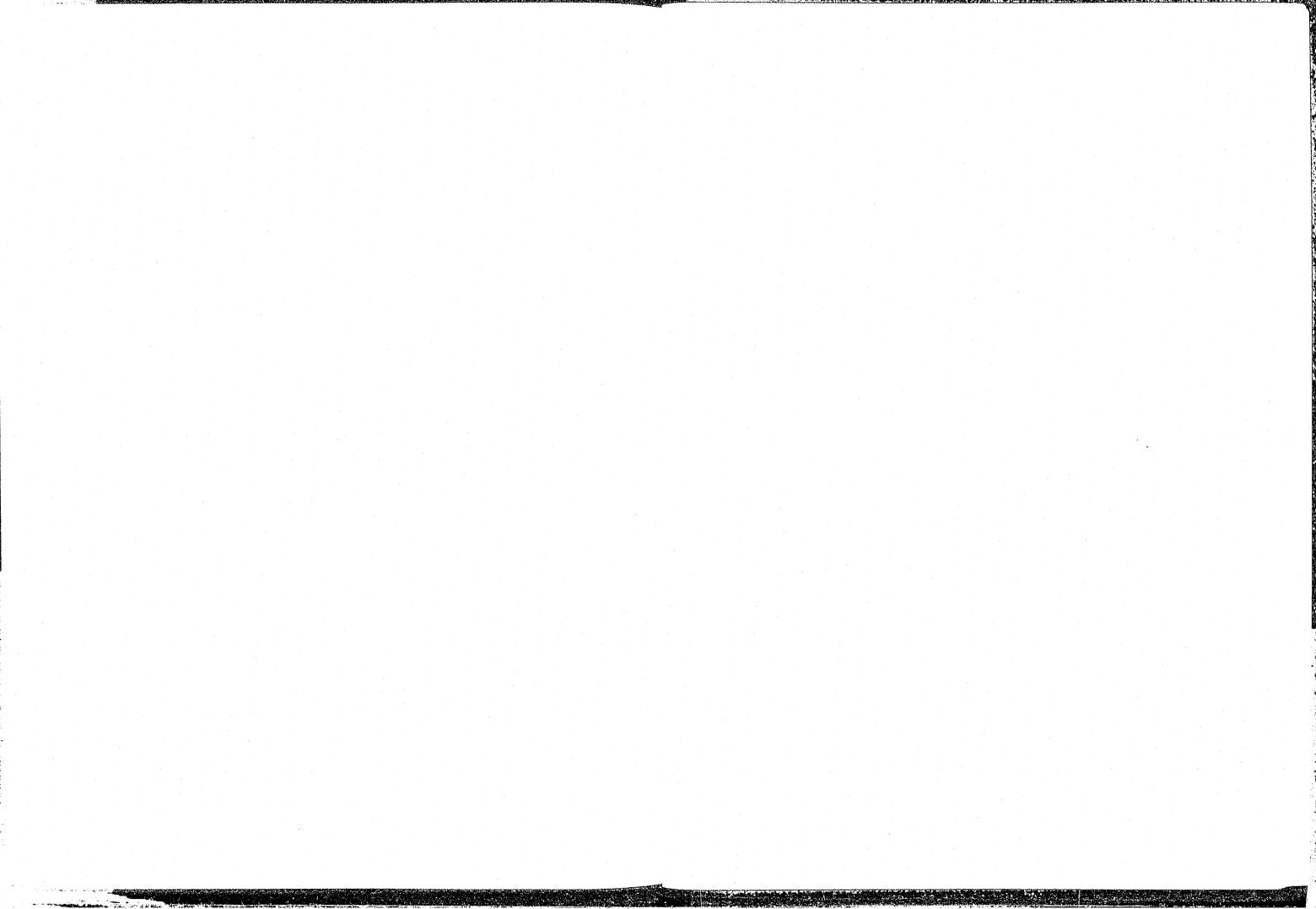
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	1	Secretary that might be relevant in terms of principles, but			1			
	2	the idea of the colloquium was to go further than that, to			2			
	3	do something very different, to have people actually look			3			
	4	at these ethical principles, so that they should not, I don't			4			
	5	think perhaps be viewed as one without the other in a sense.						
	6	DR. RYAN: The Commission can decide now if it			5			
	7	wishes to for the staff to proceed with both of these things.			7			
	8	I suspect you are going to need both of them. Do the best			8			
	9	you can with the staff report, but we are going to have to						
	10	get people in the public sector and providers and users of			9			
	11	this kind of service talking to us on the subject if we are			11			
	12	going to have any credibility of having looked at it.			12			
	13	MS. KING: The staff is to be commended for its			13			
	14	promptness, its conciseness and its worthwhile ideas, and			14			
	15	I so move that we adopt a two-page outline.			15			
	16	(The motion was duly seconded.)			16			
	17	DR. RYAN: Any further discussion?	-		17			
	18	All in favor?	-		18			
	19	(There was a chorus of ayes.)			10			
	20	DR. JONSEN: If we are going to vote, I am going to			20			
Sowers Reporting Company	21	add something.			20			
	22	DR. RYAN: We have already voted.		ź	-			
	23	DR. JONSEN: Did we vote already?		Company	22			
	24	DR. RYAN: What was it?		Reporting	23			
BOWERS	25	DR. JONSEN: It has been suggested to me that the		Bowers Re	24			
				ň	25			

Medical Research Council in Great Britain has approached this problem in their setting, and that they might be able to provide some useful information. I think Sir John Gray was the person whose name was mentioned. Does anyone -if we want a cross-cultural experience. MR. YESLEY: Could I make a suggestion, both with respect to this colloquium and possibly with respect to some activities in connection with the special study, that is a convocation of scholars that we are working on? Both of these events we might schedule for June perhaps before or after the Commission meeting. June is a good time to get together scholars perhaps after their academic duties are finished and before they have gone off for the summer so that you might, in terms of your own vacations, postpone vacations until, say, at least after the third week of June because we may have one or both of these activities in addition to the June meeting, and both of the activities are ones where while they would not be held at the meetings of the 8 9 Commission, they would be open to Commissioners' participation and observance, and as soon as we have dates we will mail Ó them out to you. DR. RYAN: I don't think your suggestions are at 2 cross purposes. They can look into that, and I don't think 3 4

they have to incorporate it into a vote. DR. BRADY: Michael can fly over to London this

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1	1 think that we might want to add that.			
. 2	DR. RYAN: Duane?		1	normal volunteers under controlled con
3	DR. ALEXANDER: This was never reported on to my		2	only in institutionalized subjects."
4	knowledge at the Commission meeting. Could you give us		3	scratch the last part of that "obtaina
5	something in writing?		4	institutionalized subjects." It is no
5	DR. LEBACQZ: Didn't we make an oral report on		5	information can be obtained only in in
6	that someplace? I thought we did, but we can certainly		6	subjects, and I think that that may sk
7			7	for the deliberations that we have had
8	give you something in writing and make sure that you get		8	necessary to use prisoners or whether
9	appropriate data to do that.		9	populations available. My most
10	DR. RYAN: Yes, I noticed that that was not in		10	DR. COOKE: There is a point
11	there, and I wondered why. I think the transcript will show		11	
12	that Al Jonsen spoke about it and perhaps Karen.			that you have to have people who are c
13	I think we did.		12	could substitute cloistered rather than
14	DR. JONSEN: As I recall		13	DR. LEBACQZ: Perhaps the wo
15	DR. BRADY: It was probably done in conjunction	-	14	better than institutionalized.
16	with one of the other reports when we were talking about		15	DR. RYAN: I think that is pr
17	DR. RYAN: But unless there is some substantive		16	DR. TOULMIN: Under controlle
18	thing, they are right. They cannot refer to it because they		17	DR. LEBACQZ: Yes, that is ri
	don't know what to say.		18	thought that if one simply stopped that
19	DR. LEBACQZ: Okay. Second, there is one		19	controlled conditions, that that would
20	sentence on page 4 that I think is misleading. I am not		20	and not have the potential for being mi
21			21	fussy at this point about what the part
^{vip} 22	trying to nit-pick. It is a more important point. The	, Luca	22	reworking of it.
) 6 23	sentence is at the top of the page in that first paragraph	3 Comp	23	My most substantive concern c
24 11		Buting		several pages immediately following und
ang 25	amendments involved evaluation of safety of new drugs in	Dowers R		the development and nature of research
		é ă	20	ene deveropment and nature or research

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onditions obtainable

I would like to able only in ot clear that that nstitutionalized kew the background d about whether it is there are alternative

t if it is correct cloistered, and we an --

ord cloistered would be

probably the intent. led conditions. right. I would have at sentence after d have been sufficient misleading. I am not cticular wording is in the

comes on page 2 and nder the discussion of involving prisoners.

I don't think that the staff is inaccurate here, but I think 1 a misleading impression is given at the bottom of this page 2 and on the subsequent pages. One gets the impression in an 3 initial reading of this that behavioral research is by 4 definition therapeutic, and I have raised objections to that .5 before and will raise them again and put them on the record 6 at this point in time and also that most of the biomedical 7 research that is done or all of it is to be non-therapeutic. 8 That is corrected at a later point. I believe on page 5 9 there is a statement made that there are non-therapeutic 10 forms of behavioral research and so on. It is misleading 11 and a bit unclear when it is first presented. Also, there 12 is a sentence that reads, "By contrast" -- this is at the 13 very bottom of page 2. "By contrast the use of prisoners 14 in innovative approaches to rehabilitation is relatively 15 recent." The implication is that innovative approaches to 16 rehabilitation is in some way a form of research, and we have 17 not established that yet, and that seems a little confusing 18 to me. 19

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DR. RYAN: That needs to be made clear.

DR. LEBACQZ: That language, I continue to be 21 troubled by the use of the term "therapeutic" in conjunction 22 with behavioral research, and I think that usage rests on 23 some assumptions that I do not share. So, at some point 24 the Commission may need to discuss whether we are going to ີ້ສ 25

even use those two words in conjunction with each other. DR. BRADY: There are no instances in which you 2 think behavioral research is therapeutic? 3 DR. LEBACQZ: Unless we want to discuss that now. 4 You might hold that discussion. 5 DR. RYAN: Let us hold that discussion in abeyance. 6 I think in addition to the kinds of things which Karen 7 was talking about which are the thrust and meaning of words 8 and so on and so forth which is important, the other is, is 9 everything in here reflective of the large amount of information 10 the staff has received, and does it accurately reflect the 11 data as we have received it, essays and so on, and I think 12 we need from the Commission members some sentiment sometime that 13 that is going in the right direction, and it needs to be 14 cleaned up. 15

DR. LEBACQZ: May I add, since I have raised several points of criticism, that on the whole I found the document to be very good, and I thought the summaries by and large were quite accurate. You could go over them all with a fine tooth comb, but they look good. DR. RYAN: That was my perception. If there is no further need to deal with this at this time except to say that you should read it and get your thoughts back in --MR. YESLEY: Could we receive those thoughts, I hope, by the end of this week, because we will go through

another revision, but I want to get started right away on it so I can get this back to you in advance of the next meeting. 2

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DR. RYAN: Dr. Jonsen?

DR. JONSEN: I wonder if in between this paper 4 and the kind of thing we worked on this morning there is any 5 need for some conclusions that we might draw out of the 6 information prior to going to our recommendations? That 7 would be something we would have to do commonly. I mean 8 an example might be the conclusion that from this evidence 9 that the experimentation which has gone on in the last 10 decade did not represent high risk, things of that sort that 11 might be drawn out of the data. 12

DR. RYAN: I presumed we were discussing all about 13 this from that vantage point, Al, but in point of fact, we 14. may have to state things much more specifically with a 15 reference back as Karen did to West's article, for instance, 16 based on this. 17

DR. JONSEN: Would we have a conclusion, for 18 example about the statement that a prison is inherently a 19 coercive environment on the basis of the information 20 presented here. Would we draw some conclusions that that 21 is true, false, needs to be distinguished or whatever? 22

DR. RYAN: Okay.

DR. JONSEN: I certainly have drawn a lot of 24 conclusions, and I have talked -- you are quite right. I have 25

for the last few days on the basis of conclusions I have drawn.

DR. RYAN: I think that we are going to have to identify them not only individually as we have discussed those but I think that the staff may out of the thread of the transcript and our discussions, identify things that the Commission, the bases on which the Commissioners are making their statements because we usually challenge one another when we don't agree, and we very often quote what we are about, so that Tannenbaum's data which we did not have available could be included, his IRB material, and I think the staff could look at it from that point of view as well. Are there other items now? The arguments for and against the participation

of prisoners in research pose the questions, but then did not give the answers based on the material. They did not want to presume to prejudge our discussion. DR. COOKE: I hope we could try to sharpen the in prison versus the involvement of prisoners in research, in prison research. I know we discussed it a fair amount this morning, but that is not the way this has developed, and it seems to me there are substantial differences. DR. RYAN: Could you elaborate? DR. COOKE: Just the differences between research involving prisoners and research carried out in prisons, and

I think there is a very great difference.

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2 DR. RYAN: What is that difference, Bob? 3 DR. COOKE: The circumstances under which the research is carried out make a great deal of difference as 4 5 far as I am concerned as to whether or not it is acceptable. and the settings, I think, are different. 6

DR. RYAN: I think that the point where we all 7 agree is that the setting -- let us use the Lilly example. 8 Is that what you are talking about?. That setting is fine 9 10 because it is open to public scrutiny. The prisoner is under no constraints then, and he is acting like someone who is on 11 a furlough. 12

13 The thing that that would not satisfy is the fact that the prisoner comes from a pool of people in a coercive 14 environment over which we have no control, and that we would 15 want to see the same kinds of safeguards. I don't think we 16 are at cross purposes. I don't think there is anyone here 17 who objects to the Lilly model. 18

MR. TURTLE: How about the safeguard though being 19 20 Bob's idea that in order to check on the voluntariness of 21 his informed consent, even if he is going into research outside 22 the prison which solves my problem in terms of the closed society, the check on the true voluntary nature of his consent 23 is half the people in that project are also volunteers from 24 25 outside. Now, it seems to me then we might be able to have the situation where you could have research outside the prisons. DR. RYAN: That is just with respect to the risks that people are willing to take as we said before. MR. TURTLE: It deals with the voluntary nature of the consent. You see, there are two problems that I think we are dealing with. One is our concern about the coercive element of prisons. The other is our concern or at least my concern about the closed nature of prison as an institution.

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It seems to me you can solve the closed nature by 10 having the research outside the prison. You still have to deal with the problem about the voluntariness of the consent, 12 and there Bob's approach serves as a check on it. That is, 13 if people in the free society will volunteer for this 14 project in equal numbers, then maybe we can assume that the 15 consent is all right. 16

DR. RYAN: I think that the only difference is, and I don't want to delay this any longer, but I do want to respond because I feel entirely different. I satisfy myself in the few places that I have been that these prisoners are pretty autonomous individuals with respect to voluntarily consenting to the kind of biomedical research they were involved in, and I don't need any other tests to test that voluntary nature of it. You know, the motivations for people outside and people in the prison are going to be

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entirely different as we know, and I think the thing that still provides a problem for me is that prisoners come out 2 of a coercive environment and then go into a place where -3 you can observe them. I am not against that and perhaps Δ we may join forces in saying that that is a good device which 5 can go on also. I wouldnot want to exclude it. I think it 6 7 might very well be one of the ways to get out of the dilemma. 8 DR. BRADY: There is a fourth cell in the four-fold table, however, and that is the case in which the non-prisoner 9 comes into a prison to participate in research. You cannot 10 overlook that if you want to characterize this the way you 11 guys are working on it. It is a four-fold table, and there 12 are, in fact; instances I probably can cite right now where 13 non-prisoners come into a prison to participate in research. 14 DR. COOKE: But it has the disadvantage of having 15 less public scrutiny. 16 DR. RYAN: That is right. It is closed. 17 18 DR. COOKE: And I think that is an advantage of the outside. 19 DR. RYAN: Right, we all agree. We want to get 20 more public scrutiny inside as well, but now --21 DR. LOUISELL: Can you lose track of the reality 22 that even though the prisoner is out of the prison's immediate 23 environment, outside the walls, he is still frequently 24 subject to many of the disciplines of being a prisoner. The 25

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1 conditions of his release, in other words, for purposes of 2 the experimentation are not a wholly effective withdrawal 3 from prison life, and therefore we have got to be very careful in these delineations. In other words, being outside 5 the four walls hopefully diminishes but does not remove the 6 problem of being subjected to prison discipline. 7 MR. TURTLE: It can even provide a greater restraint where the sole condition for which he is released is the 8 research, and if he wants to terminate the research he has 9 10 got to go back to prison. 11 MS. KING: I think what we have not addressed, and I think we should do it is in order to be a prisoner 12 13 participating in research outside of the immediate walls of 14 prison must the prison from which you have come qualify 15 under the standards? That is a very difficult question because it is conceivable to me that you can have certain 16 types of programs where it is true you are still under some 17 18 contraints, furloughs, work release programs, halfway houses, 19 we all concede that they are still under restraint. Where 20 we might permit research on the prisoner in that setting and environment and he not or she not be from a prison but 21 22 necessarily met all the conditions, that is what we need to 23 talk about. 24

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I know this was what Bob was trying to get to. What kinds of things are we willing to accept once we have

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defined -- I mean accept in terms of the pool from whence they come if we are talking about research where the setting is slightly changed or does a change in setting make no difference to anybody's mind and they would not permit any research even in a different setting unless the prison qualified, and I think that that is the issue that we must deal with.

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DR. RYAN: I think that it comes very quickly 8 up against the question of now dealing with a prisoner who is 9 on work release or furlough, still under the jurisdiction 10 of the court but in all other respects has no restrictions 11 on his activity except that he is not supposed to deal in 12 crime anymore. Presumably that would cause his going back 13 to jail under these programs. Then the question is does the 14 Commission want to start talking about that individual in a 15 different context than any other individual in society. 16

MS. KING: Yes, I do.

DR. RYAN: Because of the fact that you think the individual is going out doing research as part of his activity somehow makes him different?

MS. KING: I see the potentiality for abuse. For example, one of the things I might want to make a condition for research going on outside of prisons on prisoners would be the same provision about your sentence being changed or the final disposition in terms of how long

you have to be under correctional authority cannot be a basis for participating in the research. I might make as 2 a condition that the only way one can participate in a 3 work release program or furlough program is that you agree to 5 participate in research. I mean I can think of some things that the prisoner is still different. He or she is not a free member of society because they still are subject to have the work release revoked or the furlough revoked or 8 9 some other things revoked and being sent back to prison, and I think you have to take into account that, and I think that 10 is what Bob was saying, that we have not fairly dealt with 11 his alternative unless we begin to attempt to specify some 12 conditions under which we would permit such research. 13 DR. RYAN: I think you could join that issue and 14 probably focus it very, very sharply if you asked the 15 question if the -- and we were in Southern State Prison in 16 Michigan, Jackson, Michigan, if you took that clinical 17 research unit and moved it outside the walls --18 DR. COOKE: Put it in Ann Arbor. 19 20 DR. RYAN: You require a certain distance between the physical --21 22 DR. COOKE: No, but I am just saying that under an environment in which you have other bits of research 23 going on non-prisoner volunteers in that same setting, 24 you put it -- Ann Arbor would be the place. 25

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DR. RYAN: All right.

DR. COOKE: University participation, et cetera. What conditions would you like to see this?

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DR. RYAN: Would you approve that now and if not 4 why not and how would you change it? Yes, Stephen Toulmin? 5 To the /extent that the crucial question DR. TOULMIN: 6 would have to do with how the prisoner gets into the pool 7 of research subjects, or the arbitrariness that prison 8 administrators can exercise in controlling that it remains 9 unchanged whether the locus of research is within the 10 prison or outside, so that /at the very least/ Item 7 in our 11 list here which has to do with the participation of prisoners 12 prison in /yovernment, is absolutely essential whatever the locus is. 13 DR. RYAN: That is one concept. Brad Gray? 14 DR. GRAY: Similar to this, plus an additional 15 point. It seems to me there are two assumptions that are 16 here that I think are quite questionable. No. 1 is the 17 assumption that if prisoners are participating in research 18 outside the walls consent will be obtained outside the walls, 19 and the question that I would like to know is how do they 20 get there? How do they get selected out if one gets to 21 what Stephen was talking about? They get recruited within 22 the walls. So, whether it is done inside or outside, that 23 remains the same. 24

The second assumption that I see here, I don't

know whether it is an assumption or a completely new conception, but I have never heard of the idea -- well, let 2 me not put it that way. There is an assumption that subjects are good monitors of research and that the subjects that are 5 recruited to participate in research are to be paid and so forth in drug testing research and would be good monitors, and I think we have to look at the data we have which is the data from Kansas City on the Arnold data on who in fact get recruited into research that is done on the outside, and it looks to me like it is basically the same population that 10 is on the inside. So that is one thing, and the other thing 12 is if we are concerned about monitoring it seems to me that what we should be talking about is a direct mechanism for 13 monitoring and not saying, "Well, we will recruit subjects 14 from among ex-prisoners, and we will call them monitors." 15 16 DR. COOKE: But what we are saying is that that setting is so much more public. You have got people going back and forth. There are no constraints on the movement of 18 other individuals. There are visitors into that of non-prisoners, et cetera. The opportunity for complaints, et cetera is just 21 so much greater. 22 DR. RYAN: Barbara Mishkin, please?

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the MS. MISHKIN: To / extent that the setting is even more different when you move the research clinic outside the walls, you have increased the disparity between

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	1	that from which the prisoner comeshis need for medical			
	2	care, his need for contact with outside people, his need for			are still serving a sentence to be in
	3	all sorts of other changes in his environmentand you have			2 walk in and out. They just don't, and
	.4	then made more complex rather than simplified, it seems to me,	. '		g again, and you know, it is just naive
	5	the question of why he wants to go into the research and what		4	locating it somewhere like on a collec
	6	constraints there are on the kinds of consent he gives to		L.	it becomes a place where it is open.
	7	leave the prison environment and go out.		. ć	DR. SELDIN: I think the ope
	8	DR. RYAN: John Irwin?		7	very minimal in restrictions.
	9	DR. IRWIN: I think you are operating with some		8	DR. IRWIN: Right.
	10			9	DR. RYAN: Excuse me. Let m
	10	kind of a very, very vague mistaken notion of what that		10	Bob Cooke. Let us not keep asking tha
		outside place would be like. Unless you wanted to only		. 11	ask how that unit is used, how the pri
	12	allow persons of a certain custody which would be very,		12	what they are under, and let us put th
	13	very minimum custody, and that would be discriminatory then		13	know for a fact how it is used. May I
	14	you are barring out large categories of prisoners, the		14	to do that, and let us get it?
	15	society outside, around the place wherever it is, you know	-	15	Pat King?
	16	that there are prisons right downtown, incidentally Salem,		16	MS. KING: Let me say something
	17	Oregon has a prison which you can hit it with a rock from the	1	-17	off in 18 million directions again whic
	18	city hall. I mean it is a very closed off prison.		18	that we go off in 18 million directions
	19	Whether you mean by close to the downtown center, it has		19	Bob asked, it seems to me, a most reaso
	20	nothing to do with whether it is a prison or not. If it is		20	talk about discrimination is driving me
	21	going to be on a college campus I guarantee you that after		21	understand why it is that we cannot reg
Сотрапу	22	four weeks of operation it will have welded onto it steel		Ìn 22	way as giving incentives for people to
Reporting C	23	hars. They will have a system of controlling flow in and out		шо б 23	things on the outside, just like we wan
	24	which will be every bit as restrictive as any prison in the		keporting 24	on the inside, and it could very well be
Bowers	25	world because citizens do not tolerated convicted felons who		sizmog 25	participating in a research program on
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357 to be in a place where they can don't, and so it becomes closed ust naive to think that on a college campus and a hospital

nk the operation at Lilly is

me. Let me just respond to asking that question. Let us ow the prisoners are selected, us put that to rest so that we ed. May I instruct the staff

ay something. I see us going again which I did not intend directions about. First of all, most reasonable thing. This driving me up the wall. I don't cannot regard prisons in some people to want to do certain ike we want to reform the system ery well be a condition for have to meet all the requirements that people now meet to be
on work release programs or on halfway house programs or
whatever else has already been set up so that there are
people on the outside in certain conditions and not with
bars on the windows. That could be one of the conditions
that Bob is talking about.

The second point that I wanted to make is we are 7 talking in some sense of a balancing system. We talked 8 yesterday about insuring open communication in the system. 9 If all of us did not realize that at some level that is a 10 farce, then we really have fooled ourselves. We can do 11 everything to maximize communications within the closed 12 institution. It is still a closed institution. and the 13 last analysis the people who monitor the mail are the 14 prison officials. So, when we are talking about perhaps 15 moving the setting on the outside, maybe what you gain by 16 moving it to another environment, work release or furlough 17 programs is a better or increases, perhaps, the possibility 18 of real communication going on. That may mean that you are 19 willing to accept a decrease in some other area. I am only 20 saying that that is what we are talking about. We are crazy 21 to think that we can solve the problems of the prisons 22 by setting up all these conditions in prisons, and I don't 23 even presume to think I would have solved everything by 24 putting it outside of the prison. 25

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It seems to me if we are not going to contemplate 2 a ban on research in prisons or research on prisoners then we are dealing with a world in which we have certain 3 constraints and that we are trying to maximize certain types of opportunities. I think in fairness to Bob's proposal 5 we have not addressed what kinds of conditions would, perhaps, make acceptable the same as we did inside the prison, acceptable certain types of research. 8 9 DR. RYAN: I know, but I think that probably all that needs to be said has been said. Let us test it, Pat. 10 One was that to be sure the selection process is as fair 11 as possible, that the minimum is the prisoner should be 12 drawn from an environment where he is free to organize and 13 can bring up grievances in arbitration and to have some decision made with regard to objectives and conduct of 15 research. That is one thing. 16 Then Bob has added, but no one has either said 17 yes or no that it would be fine with him if it were conducted 18 like any other kind of research project, and the permissibility 19 for prisoners is based on the fact that non-prisoners 20 participate in equal numbers. 21 MS. KING: I said something different. 22 DR. RYAN: Then I did not understand you. 23 MS. KING: I said that I would not require the 24 conditions that we listed this morning. 25

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1	DR. RYAN: Yes, I understand.	1	was critical to keep.
2	MS. KING: That it be that kind of prison from which	-	DR. RYAN: That was No. 7.
3	the pool is drawn in order to have people be able to		MS. KING: And that was No. 7,
4	participate in research as prisoners on the outside. That	1	is what we need if we are going to give
5	is a very different statement. That means we have got to	5	guidance. I feel differently from Stephe
6	talk about what for those who do not agree with me, what it	6	necessity for keeping that precise one.
7	is about the conditions that we set out that we would drop	7	DR. RYAN: You would drop all
8	or modify to some degree if we were going to permit research	8	would you drop, Pat?
Ş	on the outside and what additional ones we would impose.	· · · · · · · · · · · · · · · · · · ·	MS. KING: I would keep 3. I
.10	Ken, if you are suggesting in the interests of time	0.	to analyze right now unless we talk abou
1	that we first get a description of those Lilly models so	1	I know some more about work release and :
1	that we work from a model because that is a more efficient	12	know what 1 means to tell you the truth.
1	use of time, I am perfectly willing to do that, if you think	13	regular access by prisoners to outside ma
1	that that is more efficient, as long as we do do that.	14	because there will be a difference in co
1	DR. RYAN: I did not understand you, Pat. Now,	15	If you are outside you can communicate w
1	1 think I do. What you are saying is okay, given that we	16	You have access to the telephone, et cet
1	are going to do what Bob said, we have got seven, only	17	DR. RYAN: But before you get o
۱	8 No. 7 was cited by anyone around the table that said I want	18	MS. KING: You see, that is my
1	9 that even for Bob's model.	19	does the prison from whence these people
2	0 MS. KING: I am saying that I may drop that one	20	these criteria.
2	on Bob's model.	21	DR. RYAN: Tell me, do you wan
1150 F.L.	2 DR. RYAN: Okay, but now you are also asking us	100 22	DR. COOKE: May I take a crack
	3 do we want 1 through 6.	ຍ 23	DR. RYAN: Let Pat finish becau
10020 5	MS. KING: I wanted to hear other people express	ntroday 24	settle it in her own mind.
	25 what it is. I think Stephen expressed what he considered	⁵² / ₆₈ 25	MS. KING: Thank you, Bob, I do
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7, and I think that give the staff any Stephen about the

all seven? Which ones

I think 2 is difficult about work release and and furloughs. I don't cuth. I think that

ide may need rewording In communication forms. te with the doctors. cetera.

get out you don't. is my point. My point is eople come have to meet

want 5 or not? crack at it? because she has got to

I do want --

DR. TOULMIN: Let me make one remark about the 1 document as it stands. The document as it stands is stated 2 in terms of research involving prisoners. The document, as 3 it stands was drawn up to apply to both classes of cases. If we are going to make a different set of rules for research 5 as it is conducted outside the prison environment we do need 6 to change the whole document. 7

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DR. RYAN: Yes, if that is the case. I think that 8 in making it up, you are right, Steve, it was our impression Q that we would not want to condone because it would be 10 whitewashing, just pulling the prisoners, those selected 11 prisoners, outside the prison to have research done without 12 really addressing the question of the environment. Now, you 13 reject that. That is a difference of opinion, but we are 14 entitled to differences of opinion. 15

Karen?

DR. LEBACQZ: It does seem to me that I don't know very much about the work with these programs and whatnot, but it seems to me that we really have to begin talking about two different institutions now, if we are going to talk about prisoners who are outside of prison and that all these qualifications which we talked about as being applicable to prison when research is done in the prison are surely qualifications that we would apply to this institution that is on the outside wherein the research is conducted. We would 25

assume that that institution would have to have all of these 2 qualifications. Then the question is in addition to that, 3 do we have some concerns that remain because of the fact 4 that people who are in this new institution remain yet under 5 the authority of the state in one of its manifestations and 6 can be taken out of that environment and sent back into the 7 other environment and also that in order to get into this 8 new institution they may have come out of another extremely 9 tightly closed setting, and I share Stephen's concern about 10 what it means to say that someone can get out of prison into 11 a nice environment if they are willing to go into research. 12 That strikes me as being quite coercive if I may use that 13 term.

14 MS. KING: No one wants to --15 DR. LEBACQZ: Just let me finish, okay? I also 16 share the concern that someone who is outside now and in this 17 nice setting is still subject to what I would call the 18 arbitrary exercise of power, and 1 still want to be sure that 19 there cannot be that kind of arbitrary exercise of power that 20 says, "If you do not participate in X research program back 21 you go into this other place."

22 Minimally it seems to me, those two extensions, if 23 you will, are present, the one that has to do with people coming out, where they come from and whether the coming out 25 could be in any way coercive and the other that has to do with

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	1	the possibility of them being sent back in. There may be						
	2	others, but those two are minimally problemmatic to me.						
	3	DR. RYAN: Let Don Seldin talk and then we will						
	4	go to the side.						
	5	DR. SELDIN: It is just an extension of Karen's						
	6	point. The dropout rate of research subjects is a good way						
	7	in part to look at overall coercions. I think the figures						
	8	we got from Tannenbaum within the prison were about 14 percent						
	9	Unless I miss my guess the dropout rate of the Lilly project						
	10	is zero.						
	11	DR. COOKE: Oh, no, it is rather considerable.						
	12	DR. SELDIN: Not when I was there. You had better						
	13	check on it.						
	14	DR. COOKE: When I was there I viewed it, and it						
	15	was rather considerable. We have someone sitting here						
	16	who I think might have some data, but it was largely boredom.						
	17	DR. SELDIN: We ought to look at it.						
	18	DR. ALEXANDER: John Arnold's rate is 1.5 percent,						
	19	very low.						
	20	DR. SELDIN: But what I am trying to say is, if it						
	21	is the case, let me put it this way, Bob, if it is the case						
Jupdu	22	that the dropout it raises the suspicion that the coercive						
ing Cor	23	overcone of being returned to prison is frightening, and that						
Bowers Reporting Company	24	possibility exists that the prisoner now in the Lilly						
Buwer	25	setting or some similar setting may be subtly coerced into						

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remaining in the research project because he faces the threat of being returned to the prison environment, and the 2 prison environment may be an alternative, while on the 3 other side of the coin the kind of person who emerges from 4 5 the prison may also be, in a certain sense, the subject of considerable bribery in the sense that he has the chance of 6 escaping from an unattractive environment. For both these 7 reasons I think one should look very carefully at an item 8 9 like 7 applying to the prison situation and a special stipulation regarding what happens in the second setting 10 11 that might coerce him to remain a research subject. 12 DR. RYAN: Thank you. I have three who want to speak over here. Pat? 13 MS. KING: I want to say that I agree with Karen 1.4 about the outside setting meeting the conditions. I don't 15 have any quarrel with that. 16 I think, however, that some things seem to be getting 17 very confused around here. We have talked already that we 18 have not removed coercion. We have not removed enticement. 19 For a prisoner a work release program is an enticement. 20 21 The difference between the work release program and an 22 opportunity to do something in the neighborhood and the opportunity to participate in a research project takes us now 23 back to the question of what is there about a research project 24 ຊື່ 25 that we may object to that is so different from work. If that

is the concern, it seems to me that maybe some people would like to think about only certain types of research may be 2 2 permitted in this setting, and that is one way to solve it. 3 3 The second problem is things that are carrots or 4 4 sticks may also be carrots and they may have a good -- I 5 5 don't see anything inherently bad about attracting a person 6 6 to try to stay on the outside of the prison hopefully go back 7 into a normal life if it is not dangerous to the person, 8 8 and I think if it is risk that we are worried about in terms Ø 9 of the risk he is taking because he will stay in a project 10 10 rather than to return to his prison environment is perhaps 11 11 something that can be dealt with by setting out conditions. 12 12 That is the second point, and I have so many points --13 13 DR. RYAN: Before you go on, Pat, I just want to 14 14 be sure I understand this. You are wondering why people 15 15 are concerned whether or not it is coercion. I don't think 16 16 it would be, and I don't think we would be discussing it if 17 17 the prisoner is given work release and is given an opportunity 18 18 to choose what he wants to do as a free man outside prison. 19 19 MS. KING: That is No. 2 in your thing if you are 20 20 talking about --21 21 DR. RYAN: But --22 22 MS. KING: Wait a minute. People go on a work 23 23 release or furlough program. Karen said the setting into 24 24 which one goes, and she did not define the setting narrowly ž 25 Ő 25

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to be only the place where the research is conducted, the setting into which one goes in terms of alternatives that one has, I said the conditions could be that you may have to qualify for work release. You may then have an option or we may require that that option be that you be able to select among types of work.

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A third one may be that the pay among the alternatives that you were given be comparable. It seems to me that what people are saying about the worry of being returned to the prison environment which may not be a good environment is some help. That fear is so coercive, and I can understand how that may be a coercive fear, but I don't understand how that differs from work release and furlough programs. People don't want to go back to prison. DR. RYAN: I don't think it does, Pat. MS. KING: Unless we are talking about the risk in the research program. DR. RYAN: I don't think it does. I think there is perhaps some misunderstanding about the conditions under which the prisoner is outside in this unit. DR. COOKE: It would be perfectly easy to assure that a prisoner would not have to return to a prison environment if he was through. He would remain for the duration of the protocol as he agreed in his contract even though he did not participate.

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Ĩ	DR. RYAN: But if he is out on work release does		
2	he have to stay on the job or go back to prison?	Ì	and c
	MR. TURTLE: He can find another job.	2	in th
3	DR. RYAN: But he is a free agent.	3	just
4	DR. COOKE: Yes, but he does not have to stay in	2	If yo
5	the research project. The worry that has been expressed	5	, about
6	DR. RYAN: That is right. He can go and get another	į	peopl
7	job.	7	norma
8	DR. COOKE: Or he might even remain in that	5	In Ca
9	environment. You could draw it up so that he would not have	Ş	In Al
10	to return to the prison if he chose to withdraw.	10	of th
11	DR. RYAN: John Irwin, please?	11	be re
12	DR. IRWIN: You are really talking about Mars	12	outsi
13	because there are some realities here that just must be	13	g publi
14	confronted. Let me make some distinctions. If you are	14	righ
15	talking about an outside unit which is available to the	1.5	thei
16	general prison population with some exceptions which we have	10	going
17	already mentioned, such as those persons who are in	17	, serv
18	isolation being established on the outside because of	 18	who a
19	something like the Lilly experiment which I have no idea	19	, last
20	what it is like, it will be different in that it will be	20)
21	more open to the public. That is pie in the sky because	2	If,
22		fund 21	2 amou
23	that just will not occur. What happens is when they build a new component	upduo 2	3 into
24		Reporting	4 one
25	for all classes of prisoners, including method	SIZMOB 2	5 are

lose custody prisoners in a new location, be it downtown e boondocks or an island, wherever, it becomes a prison like the prisons that you saw. Let me pursue this. ou are talking about work release let me tell you something t the experiences with work release. If you allow le to go on work release very far before they are ally to be released the public outcry becomes intense. alifornia it resulted in almost abandoning work release. laska it resulted in banning work release. The citizens he United States do not allow people on a large scale to emoved out of prison during a sentence and placed in some ide place where they can run around free and from the ic's viewpoint rape, rob and pillage. Washington, D.C., t here is coming under the same intense critcisms for r early release programs from Lorton. You are just not g to go over those barriers. You are going to end up icing one small percent of your population, those persons are almost finished. In California it has to be their 60 days to go on work release.

Just one more point and I am going to shut up. in fact, you have some population which has considerable nt of freedom, say work releasees, then the contamination your drug program is going to be unbelievable. The big problem with work release programs is that they are drugged. People who are released from prisons happen

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to like drugs, and they get drugs, and they are going to get drugs, and you are going to have all kinds of problems 21 doing biomedical research on people who have access to the 3 community. 4 DR. RYAN: There is no question we can get the 5 facts about the Lilly program. We should not deal in 61 ambiguities there. I think we all agree that if prisoners 7 are allowed outside the prison they are going to have to be 8 the kinds of individuals who would be allowed their freedom 9 in other circumstances in which case the concerns of the 10 Commission for that individual will probably be no different 11 than the kinds of safeguards we would want for any citizen 12 and get to our basic ethical principles. The only point is 13 the ethical consideration of how they get out and the fact 14 that the biomedical or other kind of research is just one 15 of the many opportunities they have after their release. 16 I think we all understand that. So, unless there is something 17 more you can contribute to that point we ought to find out 18 about the Lilly program, and if that is all it applies to, 19 it applies to a relatively small portion of the research 20 going on in prisons because the people who are involved there 21 probably would not be suitable for the Lilly program, that 22 is lifers and so on. They might not be, and so I don't 23 G think we have to say that we are going to consider only Rep 24 one or the other alternatives. We can consider both, but a 25

we need more facts.

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MR. TURTLE: A clarification. It goes back to the 2 3 point that Don and I have discussed off and on over the A past couple of months, and I am surprised at his position 5 today, by the way. Don has argued that prisoners have rights, and I guess I have argued that I agree that prisoners have б rights, but I don't see what that has to do with the problem 7 of whether you put research into a prison or not, because 8 people can have rights that they cannot enjoy just by some Q extrinsic influence. This is by federal recommendation. It 10 is not a question of a physical impossibility. You could 11 put it in there or you could take it out, and we are going 12 to make recommendations for a governmental agency. So you 13 are exercising authority over people, and when they don't 14 have that right, they don't have a right. They do have a 15 right, but it is a question of being able to exercise or 16 facilitate that right. What we are really talking about here, 17 I think, to distinguish it is No. 1, a set of guidelines for 18 research in prisons. That is No. 1. No. 2 a set of guidelines, 19 if we need them and we are wondering about that, some of us 20 for research on prisoners, in what way are they different 21 except for the fact that they are in prison than other people, 22 and I think the second element is the one that is causing 23 us some confusion here. It is not so much how they get out 24 or what they use to get out. That is a different problem. 25

That is one that is involved in all sorts of coercion. People will do almost anything to get out of prison. Now, 2 if this is one of the options available to them, we would 3 suggest, I suspect some of us anyway that it not be treated 4 differently than any other option. 5

The only constraint would be probably in the 6 risk-taking involved, and for that we would include some 7 sort of provision, as Bob suggested that people on the 8 outside who are volunteering for this protocol or project 9 as well, and that is it, but I think we could proceed ahead 10 if we direct our attention here to research in prisons and 11 then wait to get some information about research on prisoners 12 outside of prisons. 13

DR. RYAN: And with respect to this question of 14 having a distribution of prisoners and non-prisoners outside, 15 that goes back to a basic ethical principle of, I guess 16 distributive justice and so on and so forth, not putting 17 aside any one component of our society that is used for 18 something that all of society is going to benefit from. 19

MR. TURTLE: It is also the check that I think we would 20 like to have to answer some of the coercive aspects. 21 Obviously there is coercion in almost anything that anybody 22 volunteers to do, but that would be true for poor people. 23

DR. RYAN: That is right, and you want to make sure that poor people and rich people get involved in research

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in the same way.

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MR. TURTLE: I am not sure we are going to be able 2 to do that. 3

DR. RYAN: I am not sure that you are going to be 4 able to do the other either, but I think that that is just 5 as important, especially for biomedical research because 6 rich people as well as poor people enjoy the fruits of that. 7 I think that we perhaps could go on. We have only 8 a few minutes. If you could identify for us points that you 9 think need to be developed further and in the few minutes 10 remaining if you could identify what is different or what 11 we have to be aware of as we go from the biomedical to the 12 behavioral model, I think it would be helpful. 13 DR. COOKE: I think one of the things it would seem 14 to me very important would be to try to do what we did in 15 the biomedical area that Seldin and his group did at Elk Ridge 16 in regard to the biomedical boundary issue. The problem that 17 I see -- maybe, Joe, you don't agree, but it seems to me there 18 are a lot of individuals in the prisons that are getting 19 handled in a way that would be called behavioral therapy or 20 rehabilitation or whatever else, using various techniques 21 that I would have to say are being handled in a way that 22 is not well substantiated at all, and could be harmful to them 23 or may be for the benefit of the caretakers but not much to 24 their benefit, et cetera, and it is very easy for these 25

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institutions to go on doing that and say, "We are not doing
research," and indeed when we did a survey we found nobody
is doing research in this field at all, and yet nothing is
established, not nothing, but very little is established as
beneficial to the subjects or non-beneficial to the subjects.
It is just a great deal of uncertainty.

So, it seems to me that whatever we say in this area ought to try to put emphasis on the fact that where what 8 is done is poorly established, not well confirmed and so 9 forth that we try to encourage as much as possible this 10 coming under the research mode and subject to review and 11 subject to scrutiny and careful analysis and subject to 12 many of the conditions of the environment of the institution 13 et cetera that we are going to impose. Otherwise everyone 14 is doing to go on doing just what they are doing because 15 none of them is doing research. 16

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DR. RYAN: Joe Brady?

DR. BRADY: The issue is whether we have the 18 same kind of standards of routine and accepted practice 19 which we could fall back upon in the biomedical area and with 20 the hospital review boards. We don't have a comparable 21 institutionalized approach in the prisons as I see it unless 22 we are moving in that direction. I don't quite see how we 23 are going to get at this, except to the extent that this 24 No. 4 those standards get extended to the behavioral 25

research area.

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DR. RYAN: You mean adequacy and availability of accredited medical --

DR. BRADY: Accredited medical care. DR. RYAN: Give us a for instance. How would you word it?

DR. BRADY: You would have a review mechanism very much the same as you have now for surgical procedures 8 in Mass General Hospital, that there is a routine, as you Ŷ described to us, there is now beginning at least a routine 10 system for reviewing radical medicine and deciding when 11 the hospital board for example decides that that particular 12 procedure is innovative and should be submitted to the 13 clinical investigation division for research. 14 It seems to me a mechanism like that could work 15 equally as well in prison. The thing I objected to in the 15 implication of some of Karen's remarks that there are no 17 therapeutic behavioral -- I think by and large what you are 18 referring to in the prison it is true. They are not well 19 established procedures for that purpose, but that there are 20 therapeutic behavioral procedures that are applicable to 21 prisoners it seems to me self-evident, systematic desensitiza-22 tion for both of these and research in that regard. It is 23 a well established therapeutic behavioral research procedure. 24 So, I would vote against excluding those terms, but with a 25

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respect to the kinds of things Bob is referring to, I have to agree with him. For the most part they are not systematically 2 applied in prison.

DR. COOKE: What Joe said is very, very critical it seems to me for the issue that Congressman Quie has 5 raised. That is the very nub of the problem. In the whole 6 educational field we have got things being done that may be 7 usual and customary but not tested, et cetera, and it means 8 that behavioral research has to be encouraged very greatly Ŷ in prisons, in schools, et cetera which makes it even more 10 important that we try to establish some ground rules for the 11 conduct of this, and I am not satisfied that in the prison 12 setting as yet we have come up with this as an adequate 13 coverage for behavioral research in prisons. 14

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DR. RYAN: Don Seldin and Eliot Stellar.

DR. SELDIN: I want to take up slightly a 16 different tack. I don't agree with any of the puzzlement. 17 I am not sure in my own mind that it is clear to me how one 18 draws boundary rules between behavioral modification as a 19 form of education, behavioral therapy, behavioral research 20 and so forth, and then veering off to biomedical science on 21 the other hand, but I do think there is a very critical 22 problem that remains even assuming that we could solve that, 23 and that is irrespective of whether we say we are doing 24 research or treatment or education, irrespective of all those 25

labels, there are two outcomes which are sometimes ambiguous. One is there is rehabilitation in some sense, 2 and the other is there is pacification. Now, a great deal of the public outcry regarding behavioral modification is the fact that we seem to be or at least some people allege that there is a kind of widespread pacification of radicals, this 6 that and the other thing where there is in a certain sense 7 an attempt to change their character which has political and social overtones rather than, let us say in quotation marks, medical overtones. 10

Now, I am not sure how to draw this distinction. I really don't. I am just expressing it in a vague puzzlement, but I don't think it is unimportant. I think that one of the great public concerns with behavioral modification is just hinging around this point. Are you really pacifying something, quieting, making more socially acceptable like a nice suit of clothes instead of being 17 sloppy, like a close-cut haircut instead of long graceful hair like Al has? It is very important to distinguish between pacification and rehabilitation. I think if the staff has any ideas on it or if any of the consultants do, it would be worthwhile expressing themselves. I have tried to touch upon this many, many times, but we have not evidently 23 gotten very far and I know it is a lousy problem. There is the second point I want to make. It has to do with the

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previous item where I still do not agree with the formulation 1 2 of prisoners outside of the prison not being under coercion. 3 The threat of returning to prison if they do not continue is a threat which is in some sense different from the kind of 4 threat of taking a risk of some canger in research. It is 5 a threat that you continue the investigation on pain of being 6 7 returned to the prison irrespective of what you may think 8 about rights, this, that and the other thing, and I don't think one should neglect that. 9 There is a danger of dislocation. We should take 10

cognizance of it, and when you write it up I think that I 11 12 would like to point out to the staff that they ought to build that into some consideration. 13

DR. RYAN: Okay. Eliot Stellar wanted to --14 MR. TURTLE: Could I just respond? 15

DR. RYAN: We are done with that subject now. 16 I think we really are because we are confusing our base of 17 operation, whether that prisoner has to go back to prison 18 or whether he goes and gets another job. That is the issue. 19 DR. STELLAR: I don't know if we can settle the 20 boundary question because I don't think we have any clear 21 conception as medicine does of what routine and accepted 22 practice is. For example, an honor block in a prison is 23 a form of altering behavior, maybe pacification of people 24 a 25 who can get there and be pacified while there, maybe for

management purposes rather than the benefit of the prisoners, 1 and that has been traditional in prisons. On the other hand, 2 the kind of thing we heard at Furnall School, regrouping 3 people, new kinds of housing units which might occur in a 4 prison setting as well might be thought of as experimental. 5 I think we do have a very serious problem on that 6 half of the continuum. The other side, however, upon research, 7 including survey research, including research of an 8 experimental design, such as in the case of behavior 9 modification, I think we can begin to list those. The 10 problem is that I don't have a conception. I don't know 11 whether you do, Joe, of the continuum that actually goes on 12 in the prisons today that would represent the experimental 13 extreme at one end and the routine and accepted practice on 14 the other, whether it be educational practice or social 15 management practice, and I don't know whether the staff has 16 any way or whether John Irwin has any way of leading us to 17 data of this sort. 18 I think we are shooting in the dark. We know of a 19 few behavior modification programs, and that is about it as 20

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far as experimental behavior programs that I am aware of. DR. RYAN: We are obviously going to have to work on this. We have identified it as a problem. Before we depart I want to just be sure that staff and Commission are of one mind about what we are going to do in the interim.

1 We have taken this document and changed it a little 2 and said that the Commission recommends that the Secretary 3 of HEW should not conduct, support or approve biomedical or behavioral research unless -- and then these conditions 4 5 that we are trying to develop, the ones that are stipulated and the ones that have been added will apply to research 6 within prisons. 7

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8 Staff will also develop the concept based around 0 the Lilly model, getting those facts and analyzing the 10 points with respect to the types of prisoners that might be released, develop that, and thirdly we are going to 11 develop this boundary issue in some way or think about it 12 so that the problem that Bob Cooke has raised, that is 13 innovative behavioral modification that should be research 14 15 being introduced into practice without proper evaluation, and then the fourth item which I have requested and that is 16 validation of existing things with the proviso that we don't 17 at least to the extent that the Secretary supports or 18 conducts this, we ought to encourage him to engage in research 19 20 which evaluates or validates what is going on in standard prison methods and so on, and it should not be construed 21 -- for instance, if they want to validate the quality of 22 health care within prisons with federal money, I think they 23 have enough sense not to pay attention to us no matter what 24 a 25 we said with respect to that, but I would hope that we would

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٦ encourage them to, for instance find out what is going on 2 with health care in addition to being concerned about 3 prisoners' rights with respect to research. 4 DR.SELDIN: Just one small point to Bob Turtle. 5 I am not going to go into this business of rights, but there 6 is a terrific article in the latest Hastings Bulletin by David McKanick in which he responds to an article by Charles 8 Freud and discusses the distribution of rights in society 9 and the fact that while there is access to rights not 10 everybody has them now. I think there is a fundamental 11 flaw in your argument, but rather than go into this I want 12 to take the posture of McKanick's reply to Charles Freud. 13 DR. RYAN: Bob?

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]4 DR. COOKE: In regard to your last statement about 15 let us say evaluation research, I don't want to be silly enough to think that we prohbited it and so on, I do think 16 we have got to be awful careful if we are going to have some 17 very restrictive kinds of impositions that they are spelled 18 out carefully enough so that the investigators in the country 19 don't stop doing things that are okay. 20 Now, you will recall that when the ban on fetal 21 research was imposed a lot of people stopped even looking at 22 fetal tissues in dead fetuses because they said that that 23 had all been banned and so forth and you cannot do that sort 24 of thing. So, it does seem to me that it is very important à 25

that we not assume that the investigators and so forth -- because an awful lot of work has got to be done on prisons 2 3 and prison health and prison behavior and all the rest, and if we lay it out so that it sounds as though you cannot do 4 these things an investigator is going to shy away from the 5 prisons and the prisoners in the long haul are going to be 6 hurt by it. So, I think we have got to be careful how we 7 spell out. 8

DR. TOULMIN: Could I underline one thing? What Ŷ we are doing is making recommendations that have specifically 10 to do with the question of what the Secretary of HEW should 11 finance. I mean if another John Howard or Elizabeth Frye 12 wants to go into the prisons to do research on the 13 psychological effects of being incarcerated under extremely 14 inhumane conditions, God bless them. It may be that they 15 will have to do it out of their own pockets rather than 16 getting the research financed by HEW, but nothing that we 17 say should be interpreted as creating a state of affairs 18 in which the impression is given that people who want to do 19 that kind of thing for the good of all of us should be 20 prevented in doing it. 21

DR. RYAN: I think there is an exception to that, 22 and that is there has been before the Congress a bill which 23 would have far-reaching consequences in barring all prison 24 § 25 research and using all of the federal power to grant money

383 to enforce it, and so the Congress is going to be looking very, very carefully at the kinds of recommendations that we make and we probably should spell out those areas where 3 we think research is needed and important and will accrue 4 to the benefit of the prisoners if we could identify them. 5 DR. LOUISELL: I think that the staff will avoid 6 considerable necessity of revisions if it bears in mind that 7 a number of us come to the present position of trying to set 8 forth standards over the grave difficulty of our doubts about C any research in prison and that we are doing this in, shall 10 I say, a valiant effort to try to permit some necessary 11 research, and in the discussion it is very important not to 12 withhold strong statements about the evils of the present 13 circumstances in respect to prison research. 14 We have all been startled by these revelations 15 from the Washington Oregon experimentation, and I think your 16 caution about the Congressional interest also must be borne 17 in mind. 18 DR. TOULMIN: But, David, if there is any element 19 of humanity in this country and other Western countries' 20 approach to prisoners nowadays it is because there were 21 people like John Howard and Elizabeth Fry who went into the 22 prisons and did these things which were by the standards of 23 all that we are going them research, and if we are going to 24 set up a system under which that kind of thing is pre ented we 25

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are going to be perpetuating inhumanity not promoting

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DR. LOUISELL: That is exactly why we compromised in a sense on the effort to set forth these standards.

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DR. RYAN: Don Seldin? We will go around the 5 room. Everyone will get a final say.

DR. SELDIN: Even the notion of a moratorium has 7 consequences beyond the moratorium. Bob Cooke just raised 8 the problem of we don't want to discourage things that are 9 valuable. Well, it turns out that even though this 10 Commission has acted and the fetal research ban has now been 11 lifted, I think in the most legitimate arenas of fetal 12 research there is not a single grant been received by the 13 NIH in about how long, 18 months. It is interesting. You, 14 in a certain sense, assert a posture of fear and the 15 investigators whom you really want to encourage into very 16 tricky areas where people don't want to do research don't 17 ever think that everybody is clamoring to do the kind of 18 research in prisons or research on fetuses or research on the : 9 insanc. That is a terrifying kind of research to do, and 20 one of the major problems this Commission ought to consider 21 in considering other things is how to encourage it 22 legitimately, to be sure, but how to encourage it. We should 23 not lose sight on this. If we declare a moratorium on 24 prison research and then lift it you are apt to get no 2 25

prison research for a tremendous lag time. I am not saying 1 we should not have a moratorium but we ought to think very 2 carefully about how to phrase and formulate it in order not 4 to generate the same kind of fear amongst responsible investigators that now I think will scar the reinstitution of 5 fetal research in legitimate areas and which is characterized 6 by such paucity of research amongst the insane. 8 DR. RYAN: Pat King? MS. KING: I agree with what Bob and Don said, but 9 I am troubled by something that I guess we have not done. 10 I feel rather guilty about it myself because we are deporting 11 so early, and that is that we have got to be far more 12 specific, not about the conditions. We have not begun to 13 address the variations in types of research that we are 14 talking about. We have used primarily drug research as our 15 model. There are other kinds of biomedical research that go 16 in prisons. That is number one. 17 There are all kinds of sociological and psychological 18 research that go on in prisons, and those have got to be 19 addressed. We have to come up and say yes, no or maybe, and 20 we cannot let it all fall without discussion on something 21 that we have broadly called biomedical model. 22 I think that that is going to be a far more 23

complicated task than a lot of us have thought about, and before we have got to worry about is there a valid distinction 25

between therapeutic and non-therapeutic research in these 1 2 areas, and I guess I am really kind of pleading not to think 3 that we have accomplished so much because all I think we have 4 done is scratch the surface, and I don't expect the staff 5 to do this for us. I don't think that they have very much guidance in those areas about what they could possibly do for 6 us because we have not talked about it. 7 You may try all you want. I am just saying that 8 9 we have --DR. RYAN: We have all the reading material. If 10 you want more reading material, fine. If you want to be sent 11 to another prison --12 MS. KING: It is not that, Ken. What I am suggesting 13 is we have not done -- it is not a lack of reading material 14 now and it is not a lack of information in some areas. It 15 is a question of the Commission together discussing certain 16 aspects of these things. If staff wants to take a first 17 + crack at it, I am overjoyed to hear it, but it still means 18 that we have got to spend a whole bunch of time hitting 19 some very concrete areas, and I just --20 DR. RYAN: I think one of the ways the Commission 21 can help and you particularly, Pat, if that is an issue is 22 to identify it as an agenda item so that we can discuss it 23 early, if that kind of discussion is needed for decision 24 making, and I think other Commission members if they could 25 14

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identify that it would be helpful because we cannot imagine
 all the things that people want to discuss before they
 will reach a decision.

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4 MS. KING: They have to do that, I think in terms 5 of if we are going to have a moratorium or if we are even considering a moratorium. We have to be very clear about what 6 7 it is to go back to what Bob and Don were saying. We have 8 to be very clear about what it is that we are halting. Do 9 we want some things to continue? Maybe not. Do we want some things to go on and some things not to go on? I think 10 that is very important. We really have not discussed the 11 distinction thoroughly for one thing between therapeutic 12 and non-therapeutic research, and that, to me, presents some 13 very difficult issues, not only in the behavioral area but 14 in the biomedical area. 15 DR. RYAN: All right. 16

DR. STELLAR: You know, to this end though it seems 17 to me we are going to need a better catalog than we have had 18 up to now of the ranges of biomedical research other than 19 Phase I drug testing which I agree we have concentrated on 20 too much and indeed the varieties of behavioral research 21 that can be identified either as research or on the borderline, 22 and I think that we have very poor information as to 23 frequencies and types, if you will, and we may be laboring 24 under a view that a great deal more behavioral research has <u>ຊື່</u> 25

			 	∯րուս։ Յունի մի աներաներին համաներին է հետ համանեններին էրինը՝ համանեններինը՝ համանեններինը՝ համանեններինը է հ
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	1	gone on in prisons than has actually occurred.		n - 1977 1979 - 1989 - 1989 - 1989 - 1999 -
	2	DR. RYAN: We found none. I mean we have asked for	1	talking could I mention one other
	3	it. One of the staff did this thing on the states. Is that	2	Dr. Tannenbaum just called me bac
	4	a valid document or isn't it? It tells us in most states	3	a number of additional pieces of
	5	there is no research going on.	4	he was able to report back with s
	6	MR. TURTLE: They state that there is no research	5	that the most effective way to p
	7	going on or the state law does not allow for that research.	6	be to do it orally right now, and
	8	That does not mean that it is not going on.	7	to answer all of the additional of
	9	DR. RYAN: How do we find that out?	8	what I proposed to him and what I
	10	DR. BRADY: How do we find that out. We are	9	is that before the next Commission
	11	laboring in the dark.	10	letter detailing the additional
	12	DR. ALEXANDER: We distributed sometime ago, and	11	able to answer from the data tha
	13	it is summarized in the staff paper, a summary from NIMH of	12	going to send a letter to warden
	14	all the behavior research that they are conducting or	13	on the prisons that wa requested
	15	supporting. It gives a pretty good idea what the range is	14	that before the next Commission i
	16	like.	15	time describing what he has now.
	17	DR. GRAY: What won't be included there is the	16	DR. RYAN: I will ente
	18	sort of observational research interview and research and	17	We are adjourned.
	19	so forth that is done by social scientists and graduate	18	(Thereupon, at 3:10 p.)
	20	students for their dissertations and things like that which	19	concluded.)
: Reporting Company	21	having come just from the University of North Carolina I	20	
	22	know of one recent dissertation in the sociology department	21	
	23	that was based on interviews with prisoners, and it was	22 Company	
	23 24 25	completed last year.	- 12	
BOWZI	25	I know that kind of research is done. While I am	Buitroday 24	
			13mog 25	
	. L			

her thing, please? back. He was asked to pursue of information yesterday, and h some of them. My feeling is present that to you would not and since they were not able I questions that were raised, I propose to you right now sion meeting that he send a I information that he was hat they have. They are also ens requesting overall data ted and to try to come back with

v. Is that okay? certain a motion to adjourn.

meeting rather than taking

.m., the meeting was

