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2 CHAIRMAN ALLEN: Marshall Forstein
3 is going to share with us some testimony, trying
4 to help us out with the psychosocial issues.
5 Marshall, just go ahead and speak from
6 there.
7 DR. FORSTEIN: Thank you. Let me
8 know if you can't hear me.
9 Thank you for inviting me to participate
10 with you today. I've been told to do in about
11 ten or fifteen minutes the whole psychosocial
12 continuum. So let me be specific in some ways
13 and general in others to set a kind of tone.
14 I would like to suggest that first of all
15 the place of psychosocial needs that's plagued in
16 the AIDS epidemic has been underexamined,
17 underresearched. There has been a kind of
18 second-class citizenship to the mental health
19 personnel, support services, community resources
20 that have really, from my point of view,
21 sustained any intervention and treatment services
22 that people with AIDS and HIV infection have
23 had. So my bias as a psychiatrist will come
24 quickly through my discussion this morning.

1 I think I want to talk about both
2 psychological concerns and pragmatic concerns and
3 how they interface with each other briefly.
4 There are a couple of basic concepts that I think
5 are underlying our discussion. One is that as
6 human beings there is a lot of evidence now both
7 biologically and psychologically that we don't
8 function real well over the long haul; that we
9 are really more crisis-oriented, Baby Jessica
10 Syndrome sort of is our forte. We treat the baby
11 in the well but not the hundred thousand kids who
12 are starving on a chronic basis. Our biological
13 systems are really geared that way.
14 When we have a crisis our adrenaline
15 rushes and we are great until we accommodate to
16 this level of adrenaline. That conforms, in a
17 sense, how we respond to aspects of the epidemic
18 as a care provider group. But it also conforms
19 to how individuals respond to changes in their
20 environment; such as psychologically, when they
21 hear the news of an HIV positive test. We have
22 to distinguish between acute and chronic
23 psychological and social responses to information
24 that people acquire somewhere in the spectrum.

1 The other thing is that for individuals it
2 is very hard to tease out knowledge and
3 intrapsychic motivation and defenses against that
4 meaning of knowledge in their lives. We cannot
5 extrapolate from one group of people to another
6 that the way people manage information is
7 necessarily the same.
8 So when we look at what testing means in a
9 white middle-class gay male community, which has
10 a very different environment, social structure,
11 support system, to an inner city black or
12 Hispanic community, the research data is
13 essentially useless to making really valid
14 generalizations or recommendations about how we
15 should then mobilize resources. I think there
16 has been a real need to look at the difficulties
17 in studying the meaning of the disease and
18 testing the population.
19 Likewise, when we hear about women who are
20 infected who have had children and have a second
21 child, how do we begin to understand the
22 intrapsychic or the psychological meaning of
23 disease in peoples' lives because that's what
24 makes people do what they do, not the knowledge

1 that they have about early intervention or what
2 the test really means today or what it will mean
3 in five years. There has been a kind of
4 frustration on my part that because the
5 psychological component of peoples' lives is so
6 complicated that we tend to simplify our response
7 to the crisis by underplaying its importance.
8 Let me give you an example. We know that
9 certain people after they get tested mobilize
10 their behaviors because of the test. We also
11 know that the people who are able to do that were
12 probably more able to mobilize their behavior
13 change before the test and that the test was
14 really culminating a series of psychological
15 steps that led them to that capacity.
16 Well, one of the things that go into
17 mobilizing information in what we might call a
18 pro-life, I hate to use that word, a positive
19 life force, a future orientation, and I think
20 that we really have to look at a series of
21 psychological substraits. One is the capacity in
22 people to believe that they have power to do
23 something with the information that they gather,
24 and that will obviously vary according to

1 peoples' perception of access to care, access to
2 pay for the care, and whether that in fact is
3 going to be guaranteed over the long haul.
4 If you think about the HIV continuum, it's
5 possible for someone to get anonymously tested
6 and then maybe have ten to fifteen years of
7 asymptomatic life, but that doesn't mean that
8 there aren't severe disabling psychological
9 components to their life that in fact would be
10 much more expensive to treat with the knowledge
11 that they are positive than with the apprehension
12 that they might be positive and going on
13 negotiating the daily needs of their lives.
14 None of the research data looks at people
15 who are tested more than a few years out. We
16 don't have data, for instance, what happens to
17 people four, five, six, seven, ten years down the
18 pike. The analogy I would like to use is for
19 those of you who have been on diets before, we
20 are essentially asking people to go on a diet and
21 never cheat for their entire life. Unlike a
22 diet, cheating may be lethal. If you gain a few
23 pounds, you can undo that damage by losing a few
24 pounds. If you stop smoking you can regain your

1 cardiovascular condition.

2 But the real terror in peoples' lives that

3 is integrated into the fabric of how they respond

4 to the knowledge of their seropositivity is that

5 it has an acute phenomenon and then it gets

6 changed over time.

7 So in my clinical work, for instance,

8 there are significant numbers of people who find

9 out that they are seropositive and do very well.

10 They mobilize resources, get their physician on

11 board, go into trials, find out, read more about

12 AIDS than I have. Then a year later they become

13 depressed because the magical thought that

14 somehow what they have done will now rid them of

15 this disease confronts them head on.

16 Depression is a major mental illness in

17 this country that effects all socioeconomic

18 stratum, males and females. It's the

19 undertreated illness of our society. 20 percent

20 of Americans will have major depression in their

21 life. Only 2 percent of those people will be

22 treated adequately. People who are at risk for

23 HIV we know have a much higher incidence of

24 depression, anxiety disorders, panic disorders,

1 all sorts of adjustment disorders. And some
2 research now shows that people with HIV infection
3 have more psychological impairment than people
4 with AIDS/ARC. There is something about the
5 uncertainty of one's life, the unpredictability
6 of the course of the illness that makes it very
7 difficult for people psychologically to manage
8 not necessarily in the acute phase but over the
9 long haul.
10 So the kind of continuum of care we're
11 talking about has to envision a changing need in
12 an individual and in a community from the
13 beginning of the awareness of testing and its
14 implications throughout the process of trying to
15 access care, maintaining what I would call a
16 positive future orientation.
17 If we in fact encourage people to test and
18 the first two years they do better and the next
19 eight they do worse then they might have done by
20 not testing, then what have we accomplished? And
21 if in fact someone is seropositive, we then have
22 to go the whole oute of assessing immunological
23 status, besides the access to care, the cost and
24 all of that.

1 What do people need psychologically to
2 manage the day-to-day awareness that they are now
3 part of a health care system for maybe ten years,
4 but they are not sick? What motivates people to
5 stay -- how many of you go to your cardiologist
6 gist because your heart feels great? We have to
7 look at how people utilize health services, what
8 gets them into them, and what maintains peoples'
9 diets. What is going to keep people
10 psychologically prepared to not just treat the
11 baby falling in the well, but the kids who are
12 starving down the block? And if you turn that in
13 terms of the individual, how do people maintain a
14 long-term positive view of their own life?
15 Now, I think there are some psychological
16 things that contribute to this. One is that
17 there is a direct corrolation between self
18 esteem, empowerment, and the capacity to maintain
19 what I would call a future orientation, even in
20 the face of potentially dangerous information. I
21 think we cannot talk about HIV positivity,
22 testing, and the emotional needs without looking
23 at the underlying social conditions that are part
24 of peoples' intrapsychic fabric. When I'm

1 talking to a young black male in Roxbury, and
2 he's telling me that he's more afraid of being
3 shot than of getting AIDS, that's part of his
4 psychological makeup that informs the kinds of
5 behavioral changes that he is able or not able to
6 maintain because sexuality and drugs we know are
7 extraordinarily effective anxietal lifts. We use
8 them to reduce anxiety.
9 So if we are going to ask people to
10 participate in a continuum of care, to gather
11 information about their life which makes them
12 more anxious, we then, in order to prevent the
13 behaviors which transmit AIDS from becoming more
14 intensified, we have to provide care that reduces
15 peoples' generalized anxiety about their lives.
16 And that is why I think we haven't been able to
17 pay attention to the psychological needs because
18 we can't talk about testing without talking about
19 violence, poverty, day care, mother/infant
20 mortality, and all those issues.
21 I think our own anxiety around the table
22 is probably rising as we throw back into the hoop
23 all of the social dilemmas that confront us.
24 Just a couple of pragmatic issues. Once

1 we test people, it seems to me we have an ethical
2 responsibility for following through to the
3 natural end of the meaning of that test. For
4 some people, testing will lead to positive
5 changes in their lives; to some lives it won't.
6 Are we prepared to provide the psychological
7 mechanisms to support people over the long haul?
8 I say this with a great deal of cynicism, as in
9 my own state mental health service is being cut
10 back to the point where they are going to be
11 essentially non-existent in any meaningful way.
12 The mental health cost of crisis intervention,
13 long-term care, in different kinds of communities
14 who have different perceptions of what mental
15 health means in their community, has got to be
16 looked at, and I think has got to be a major
17 focus if testing is going to have any real value
18 in forestalling the epidemic, if that is the
19 purpose.
20 The other issue is just because people
21 have access to care, assuming that doesn't mean
22 that they are able to participate in it. I have
23 had a number of people who have done all the
24 right things based on all the right information,

1 and a year into their AZT are unable to continue
2 to take it because the meaning of it on a daily
3 basis is that they are facing their mortality in
4 a way that they are not psychologically prepared
5 to do. I think it's very hard to tease these
6 things out.
7 The other thing I'll say is that from a
8 practical point of view, we have people who come,
9 decide to get tested, and then appropriately
10 realize that, they do that anonymously, but then
11 appropriately realize they have to go the next
12 step to immunological status. So they go and get
13 their T-cells tested. Who pays for that? If
14 they put it on their insurance, they are
15 asymptomatic, they may be fine as long as they
16 hold their present jobs. We are finding out that
17 premiums on people who get T-cells tested are
18 going up. We are finding that people are being
19 denied individual group policies because the
20 insurance has paid for an T-cell test. Well, we
21 don't need to fool insurance companies. They are
22 not stupid. They know that people who get T-cell
23 tested in 1990 are at risk for HIV.
24 What are we going to do in terms of

1 guaranteeing that people have access to care and
2 the ability to pay for it? If we have gotten
3 somebody into early intervention and they lose
4 their insurance three years down the line, what
5 about the ethical responsibility to continue to
6 provide care for people over the long haul? I
7 think especially as we move towards earlier
8 intervention, we are really increasing the
9 latency period of when people are going to be
10 needing surveillance for their HIV status,
11 intervention, and then treatment in a more severe
12 form.
13 Lastly, I want to bring up the notion of
14 suicide because this is not well-researched or
15 documented. There are some studies that have
16 thought that the increased incidence of suicide
17 in people with AIDS, overt AIDS, is probably
18 secondary to organic deliriums and the desire to
19 end extraordinarily painful situations. We need
20 to distinguish between the wish to end pain and
21 the wish to end life, on the terminal end of the
22 spectrum. But early on in the course of HIV
23 infection, the need to have power over one's life
24 is often expressed in terms of suicidal ideation,

1 which is very common in people with any chronic
2 illness.
3 There seems to be a much higher incidence
4 of suicide completion in people who get tested
5 who don't have the resources to help manage the
6 information over time, and those suicides do not
7 occur necessarily in the acute phase of testing.
8 So that research that looks at what happens in
9 the first five weeks of testing may not pick up
10 what we have seen from some army studies that the
11 incidence of suicide increases more towards the
12 6- or 12-month period of time, when again this
13 notion of magical work that I've done is not
14 going to prevent me from being ill.
15 So long-term studies around suicide and
16 how it's managed is very important. From my
17 perspective, it seems to me that if we are
18 advocating testing for early intervention, early
19 intervention has to include mental health
20 intervention because to separate that out is to
21 put people, I think, at higher risk for
22 significant psychological morbidity.
23 Let me stop there and lastly just say I
24 think one of the biggest issues we're facing is

1 that mental health care in this country generally
2 is underfunded, underpaid for, $500 in
3 Massachusetts is what you get for the year from
4 Blue Cross. Most insurance companies may be up
5 to a thousand, and that does not go far enough to
6 pay for basic mental health services. I think
7 there is clearly a problem in the community
8 mental health centers where mental health funding
9 is totally inadequate for present situations. To
10 add AIDS is to quickly overwhelm a system that is
11 not prepared. And additionally, having money to
12 train people in the specific issues around HIV
13 mental health issues is not forthcoming. I see
14 that as a real issue.
15 The last thing is that self esteem has to
16 do with whether you believe you're wanted in this
17 world. When your government says you are
18 illegal, immoral, you are not entitled to the
19 same rights and privileges as other people, you
20 cannot develop healty self esteem. The
21 psychology of depression for people of color, for
22 gay and lesbian people, for people with
23 disabilities, has got to be addressed or we're
24 dealing with a psychological phenomenon that is

1 larger, I think, than a specific program can
2 manage to make up for.
3 CHAIRMAN ALLEN: Thank you. Any
4 questions?
5 MS. AFFOUMADO: I want to say
6 bravo.
7 (General applause).
8 MR. LEVI: It was wonderful,
9 Marshall. I just want to add one thing for the
10 record because I'm not sure that we are going to
11 be discussing this here, and I think it's
12 important, though, that in considering these
13 issues that the Commission at some point address
14 the issue of third-party payors and,
15 particularly, private insurance companies.
16 And I can't underscore strongly enough
17 what Marshall said about the risk, the jeopardy
18 people place themselves in once they are entered
19 into the health care system; that we really have
20 only resolved the very first piece of early
21 intervention and protecting peoples' third-party
22 payor rights, and that's through anonymous
23 testing where it does exist. And he's absolutely
24 correct about once the T-cells are in peoples'

1 records that insurance companies are going to
2 look for ways to deal with it.
3 There is also, it is not just that you may
4 be forcing people to stay in a job for the rest
5 of their lives so that they are able to protect
6 their group coverage. When employers change
7 insurance plans, the individual could be staying
8 in that same job, and given how insurance rates
9 are skyrocketing, employers are much more likely
10 now than they used to be to be switching
11 carriers. When they switch, there are
12 pre-existing condition clauses. And, so, you
13 could have been there for ten years, your
14 insurance company switches carriers, and you have
15 to go through a 6-month or 12-month waiting
16 period before you are able to resume coverage for
17 a pre-existing condition. And if you had a
18 T-cell test done during that 6- or 12-month
19 period, or conceivably sought any kind of medical
20 care that ex post facto could be perceived as
21 related to HIV, you know when you start making
22 serious HIV claims, whether it's to get AZT or
23 anything else, that company is going to go
24 looking in your record to find ways to get out of

Insurance Scams

1 it.

2 And your employer may be helping you along

3 because one of the reasons, particularly in small

4 companies where there is already an incidence of

5 AIDS, that is what's going to drive up some of

6 the rates. It's going to cause a switch in

7 plans. And the plan itself may not only deal

8 with pre-existing condition clauses but may try

9 to be sufficiently restrictive so they don't have

10 to deal with the AIDS increases again.

11 CHAIRMAN ALLEN: I would hope that

12 we can get into that. I feel uncomfortable

13 because I would like for everyone to be able to

14 respond to that because that is an important

15 issue. I feel like we're kind of stifled here

16 because we're going to be asking him questions.

17 So we may want to move back into that as

18 we start the group process. Are there any

19 specific questions?

20 MS. AFFOUMADO: I would like to

21 talk a little bit about a point that you brought

22 up which I think is very important, this whole

23 idea of people taking control and then finding

24 out that this isn't working.

1 I would like to extend that a little
2 further because I think it also impacts on the
3 providers, the other types of providers that are
4 taking care of these people. And it's this mixed
5 message kind of stuff. We've been trying to form
6 partnerships with patients, between social
7 workers and nurse practitioners and doctors and
8 all of the people that are taking care of these
9 patients. And what happens is that at the point
10 where they feel that it hasn't worked, whatever,
11 it is hasn't worked, there is a tremendous amount
12 of anger between the patient and the other kinds
13 of providers.
14 It also has a strong impact on the people
15 themselves, the service providers, because it
16 adds to this level of hopelessness and
17 helplessness, and the feelings of burnout, and
18 also makes us feel dishonest because we want to
19 give that hope and want people to start working
20 towards a more positive end, knowing in the back
21 of our minds that maybe this is not going to
22 really work out because we have no way of judging
23 who is going to fall by the wayside and who
24 isn't.

1 I would also like to suggest that that
2 idea really has to go into the service providers,
3 other than the mental health providers, because
4 doctors, especially traditionally, don't have
5 that kind of training and that kind of ability
6 and support to handle those kinds of encounters
7 between their patients. It's very serious.
8 CHAIRMAN ALLEN: I have a question,
9 but we'll go around first.
10 DR. ST. JOHN: You spoke about the
11 intrapsychic environment a little bit. I was
12 curious to know in the literature and research if
13 what is known about the intrapsychic environment
14 of people after they find out about the test,
15 they may fall into one or two groups, start to do
16 something about it; and then there are the ones
17 who deny, ignore, because of minority. It's not
18 quite that dichotomous.
19 But what is known about the people who
20 don't seem to respond to this information in the
21 short run and long run? What is the intrapsychic
22 environment, in the background, their personality
23 structure, their life, that allows them not to
24 respond?

1 DR. FORSTEIN: I think I can make
2 some guesses. But, again, the research on this
3 is very complicated because it's mostly dependent
4 on self-support. We know how it is partly
5 influenced by what they imagined the person
6 getting the information is going to do with it
7 and how it will affect their continued
8 participation.
9 For instance, in the AZT trials that were
10 going on here in Boston, patients were telling
11 their researchers that they were taking their AZT
12 every four hours. Well, I was working in
13 individual treatment where at least five or six
14 patients, and maybe up to ten of those people
15 during the course of the study were not taking
16 their dose while they were asleep but they were
17 telling their provider that they were because
18 they were afraid they would get kicked out of the
19 study. The providers would therefore tell that
20 they took the medication every night at the same
21 time. But to them, what it was like getting up
22 in the middle of the night and taking a pill, of
23 being reminded of your mortality than sleeping
24 through the night and not taking the pill.

1 If we get back to what goes on in peoples'
2 head who can't respond, we're talking about an
3 extraordinary range of personal capacity in this
4 country. There are people who are very
5 sophisticated and they are creative with anxiety
6 in their life. Others are not. I think it
7 depends upon how much stress they are already
8 experiencing.
9 When someone is experiencing poverty, ill
10 health, possibly being evicted from their home,
11 to put HIV on top of it is to either overwhelm
12 the capacity to cope, so nothing gets dealt with,
13 or denial has to set in to deal with what is
14 necessary and what is not. We are much better
15 dealing with short-term stuff. The woman who is
16 being battered by the husband because she wants
17 to use condoms is more concerned about being able
18 to put food in her kid's mouth than the
19 possibility of getting AIDS three or five years
20 down the line.
21 It's this problem of how people look at
22 long-term gratification than short-term means.
23 The other is basic self esteem and the
24 feeling of whether you have a right to take care

1 of yourself. And you have a right to do things
2 that others don't want you to do.
3 And that, I think, we don't have a lot of
4 literature on. Certainly in terms of the
5 addictive population, the whole idea of when you
6 test people. In early sobriety, testing can get
7 people to feel really hopeless and relapse. We
8 have people who are able to act appropriately
9 sexually until they find out they are tested.
10 The knowledge of knowing they are positive as
11 opposed to thinking they are positive, kicks them
12 over the boundaries.
13 For some people, intellectually what they
14 believe and what they are emotionally able to do
15 doesn't coincide. People tend to handle HIV the
16 way they handled other stuff in their lives. So
17 if we look at a population who has had trouble
18 maintaining a positive self esteem, regard for
19 life, it's unlikely that HIV is going to redo
20 peoples' basic personalities behaviors.
21 That is what I wanted to say.
22 MS. GELFAND: I think one of the
23 things that we need to address overall is
24 society's attitudes towards seeking mental health

1 to begin with. If you walk in to any group that
2 we have at the center in L.A., it's predominantly
3 middle class, white gay men. And when the
4 Minority AIDS Project or one of the other
5 communities of color try to put together a
6 support group, they are not well attended; the
7 whole concept of mental health is shunned. Even
8 the women's support groups don't seem to get the
9 bodies that they need to get.
10 So I'm not quite sure how we can address
11 that. But if you're looking at the HIV disease
12 in its totality, including dimentia, that has to
13 be included in the overall picture, financially
14 as well.
15 MR. GOLDMAN: Dr. Forstein, much of
16 what you had said could be implied with virtually
17 any kind of disease as well as HIV disease in
18 terms of the acute versus the long-term response,
19 in terms of the question of the response based
20 upon whether the inherent levels of family
21 support and psychological support and
22 pre-existing psychological strength of family,
23 and the structure, the changing needs over time,
24 the issues of self esteem and empowerment, could

1 you identify anything that is specifically
2 different with HIV disease that do not apply to
3 any other chronic disease?
4 DR. FORSTEIN: Well, I'm not sure
5 --
6 MR. GOLDMAN: My question is is it
7 a general problem that we deal with HIV disease
8 and we deal with all of the other problems that
9 we have in dealing with chronic disease?
10 DR. FORSTEIN: No, I think there
11 are some differences, although they may overlap.
12 One is there may be a considerable period of time
13 that people feel absolutely well. That is
14 different from a chronic disease in which there
15 may be acute and intermittent exacerbation of
16 symptoms. It's totally possible for people to be
17 without symptoms for ten years, but know they are
18 carrying this virus and that has day-to-day
19 ramifications.
20 So in that sense this is a very different
21 kind of experience emotionally for people.
22 Another issue would be the stigma attached
23 to carrying the diagnosis and the legal issues.
24 This is especially true for many of the gay men

1 who have this disease, where acknowledging they
2 have the disease is admitting their legal status
3 in their own states, in many cases; the kind of
4 stigma associated with that, losing their jobs.
5 People with other chronic diseases are
6 more easily covered by discrimination acts and
7 are more clearly perceived by the general public
8 as being rightfully indignant when their disease
9 becomes a problem in terms of the employee and
10 housing.
11 I think homophobia, the feeling that
12 society has maintained is still very powerful.
13 That doesn't only apply to HIV disease, but the
14 interface of HIV and sexuality and drugs make for
15 a particularly powerful triad that is not present
16 completely in that regard in most other chronic
17 diseases.
18 I think, for instance, we would learn a
19 lot about how to manage other chronic diseases,
20 certainly, for dealing with HIV. But I think
21 there are some special issues.
22 CHAIRMAN ALLEN: Eunice had a
23 question and I have one, and then we are going to
24 get Marc in here and we can jump off on that and

1 much of the dialogue can take place in that

2 foundation.

3 MS. DIAZ: Yesterday, Alan Hinman

4 from CDC covered with us at the beginning of his

5 talk some of the very basic concepts that are

6 going to be part of the upcoming Centers For

7 Disease Control "America Responds To AIDS", new

8 information campaign to the general public.

9 In view of what he said and what I've

10 heard you say this morning, I really have some

11 very disquieting concerns now because I'm

12 thinking that perhaps when a message is of such

13 broad-reaching focus in this country, urging

14 people to consider to be tested for early

15 treatment and intervention may in fact cause some

16 of these individuals you've described here some

17 of the anxieties and sequellae that we are just

18 not prepared at this time to handle in this

19 country.

20 And basically there were about five

21 messages that were rather important for that

22 campaign, but the one I remember the most was

23 something you've dealt with this morning. I'm

24 just wondering, in your opinion, what would be,

1 what could be the mass effect of something like
2 this if it were to go to the public, general
3 public, such as the previous messages that we've
4 had through the campaign?
5 DR. FORSTEIN: My biggest fear will
6 be that you will get people -- first of all I
7 think we're overestimating the power of the
8 government to tell people how to live their lives
9 anyway. Even the Public Health Service putting
10 out this directive showing that you should get
11 tested, I'm not as worried about the impact of
12 that as maybe most people are. But for those who
13 do, I think the dangers are real.
14 I think that the people who want to do the
15 right thing and then find that there are all
16 sorts of reasons why they can't get the early
17 intervention treatment, nobody is going to pay
18 for it, that their families are going to be
19 ostracized, that their children are going to be
20 identified as having to be tested, it's a
21 spiraling effect. I think we are going to see a
22 psychological fallout that is much greater than
23 what we anticipated in a mental health delivery
24 system that is not capable of meeting the present

1 needs of Americans.
2 There is going to be damage. To what
3 extent? Even if it's 2 percent, if you take, you
4 go and test 50 million Americans and you have 2
5 percent who are going to have some acute untoward
6 sequellae, that is a significant blow on an
7 understaffed, underfunded mental health system.
8 I think I wouldn't be surprised if we see an
9 increase in simple dysfunction, which shows up as
10 job problems, unemployment, people taking sick
11 time. The cost of it is, I don't know how to
12 begin to estimate it. I think we have enough
13 data to suggest that without the access to
14 ongoing care, the damage will be worse, even with
15 the best system in place.
16 Let's not be naive about this. There will
17 be casualties of war, in a sense, even if we put
18 in the best possible mental health system because
19 of what some of the issues are that some people
20 can't make use of. Ethically, from my
21 perspective, we have to have things in place that
22 allow people access to the treatment they need.
23 MS. DIAZ: From your mental health
24 perspective, how could the need of informing

1 people that there is a test available, how could
2 that be reframed so that individuals would know
3 where to go for the next step? Might that be a
4 message indicating that they should enter
5 counseling or seek out a counselor?
6 DR. FORSTEIN: Absolutely. I think
7 anonymous testing sites are being advised to
8 spend less and less time with more people.
9 Twenty minutes of pre-counseling is not
10 sufficient. I wrote the program for
11 Massachusetts. It was a half hour. I regret the
12 day I wrote that. My learing since then has told
13 me that you cannot in a half hour cover the
14 details of the test much less the long-term
15 ramifications.
16 I think if we are going to advocate that
17 people get tested, we have to look at early
18 intervention psychologically as just as
19 legitimate and provide them. What we have
20 devised here in Boston is the recommendation that
21 people understand what they need to manage the
22 information, decide if they have that in place or
23 not before going to get tested, and, if not,
24 perhaps to work towards putting that stuff in

1 place before. I think ethically we need to tell
2 people as we do with a surgical procedure that
3 HIV testing is not a benign procedure, that it
4 has long-term consequences as well as short-
5 term, and people need to realize that there is a
6 potential for long-term psychological effects.
7 I do not think that HIV testing is benign,
8 even though it can be very helpful for testing.
9 And we need to see it as intervention that
10 carries with it the same kind of potential
11 untoward effects as telling people you only have
12 a 3 percent chance of dying on an open-heart
13 surgery table, but it's a 3 percent chance.
14 People who are in mental hospitals, people
15 who are wards of the state, people who are in
16 acute medical crises, people who are in addiction
17 treatment centers, how do we begin to estimate
18 what informed consent is in people who are
19 already feeling psychologically stressed? I
20 don't think someone in the middle of addiction
21 treatment can give informed consent about
22 testing. When the test is done is almost as
23 important as whether it's done, how it is done.
24 CHAIRMAN ALLEN: One of the

1 questions I have is the issue of dimentia, and
2 something we need to look at and I would like
3 your insight into that progression.
4 To the individual, I know that many people
5 that I've talked to say I don't mind dying, it's
6 just I don't want to lose my mind, that fear and
7 that anxiety and that slowness of the
8 progression, and the markers that frighten people
9 and all of that.
10 Could you address some of that? DEMENTIA
11 DR. FORSTEIN: Sure. Again, I
12 think it's difficult to separate out the
13 individual psychological response from the
14 context that the person perceives he or she is
15 living in.
16 As an example, I think since HIV tends to
17 strike mostly young people who are not accustomed
18 to thinking about losing their mind, it raises
19 terrors that developmental periods of time would
20 normally begin to prepare people to accommodate
21 one to the realities of the world. But that is
22 in a social setting in which we as a nation have
23 abandoned people in their elderly years. We
24 overmedicate people instead of treating them for

1 mild dimentia, so that people who are young say I
2 have seen what my grandmother has gone through, I
3 know she's not well cared for in the nursing
4 home, I'm not going to get that dependent.
5 Our culture has said it's okay to be
6 dependent as an infant, but not at the other end
7 of life. There are strong prohibitions about
8 dependency, about losing control over one's life,
9 and personal reasons for not going into a home,
10 like wiping out your family's resources. There
11 are many reasons why people would prefer to end
12 their life prematurely. I think that's
13 complicated by the real fears people have of
14 losing cognitive function. That is terrifying.
15 I can't say it any other way, but it's
16 simply a terrifying experience for any human
17 being to find they are losing control over one's
18 life.
19 CHAIRMAN ALLEN: Do you find that
20 in increments, in the physiological station of
21 the dimentia?
22 DR. FORSTEIN: Yes.
23 CHAIRMAN ALLEN: In that
24 progression, the intensity of that, what happens

1 to the individual? Do they disengage from life?
2 DR. FORSTEIN: It's variable. I
3 think unlike Alzheimer's disease, many people
4 with Alzheimer's get very anxious about the
5 diagnosis, have a period where they are disturbed
6 by it, but because Alzheimer's quickly damages
7 cortical functions the patient often becomes
8 unaware of their own environment.
9 This is a far more disturbing disease for
10 the family than it is for the patient. It's far
11 more disturbing emotionally for people who care
12 for Alzheimer's patients than the patient
13 itself. With HIV dimentia, in those in which it
14 develops slowly and chronically, people maintain
15 high levels of intellectual function, although
16 specific areas of cortical involvement, including
17 good memory, slowness in thinking, changing sets
18 from one kind of discussion from another. But
19 the person is often mostly aware that this is a
20 slow degenerating -- it's like watching someone
21 chop off a finger and then another finger, but
22 you know what's happening to you. I think that's
23 a much more terrifying situation.
24 Again, medical problems intervene and

1 precipitate changes in the cognitive impairment,
2 too. So it's unpredictable.
3 I think another issue is that most people
4 do not have access to psychiatrists who can, I
5 think, medicate and help with the dimentia.
6 There are things we can do to forestall the
7 dimentia and to make people work at a higher
8 level, but the access to that care isn't
9 forthcoming as well.
10 And lastly, I think there is a real clear
11 message from society for people who have HIV
12 infection that if we are not taking care of them
13 really in their best state, what can they expect
14 us to do when they are impaired.
15 CHAIRMAN ALLEN: One of the
16 concerns that I have, especially around the
17 testing issue, one of the arguments, and you get
18 down and dirty here, is because you need to test
19 certain occupations due to the dimentia. I would
20 like for you to address that.
21 But there is also the other side of an
22 individual that is into denial or at least living
23 with the secret agony of this progressive loss
24 due to the fact that I'm scared I will lose my

1 job, even if I'm protected to a certain degree.
2 Of course, you have the bona fide job
3 qualifications and the law, and so forth; that
4 that's frightening as well.
5 But I would like for you to address this
6 mentality of testing for protection rather than
7 prevention, actually.
8 DR. FORSTEIN: I think you are
9 raising what has been an ongoing debate for a few
10 years now and carries much emotional baggage with
11 it. There are some very good studies that have
12 shown over the last few years coming out of Los
13 Angeles, Chicago, New York, that when a person is
14 HIV infected, we used to think that early in the
15 infection there was a higher incidence of
16 cognitive impairment.
17 Now, the neuropsychological studies that
18 corrolate cognitive functioning with
19 immunological status, T-cell levels, and basic
20 neurocognitive motor tasks, have shown that when
21 somebody is immunologically competent, meaning
22 until the T-cells are probably below 400, there
23 is very little likelihood of HIV dimentia. It
24 doesn't mean it can't happen, but it's much

1 rarer. In fact, the notion that 10 to 20 percent
2 of people when they got infected wouldn't have
3 cognitive problems right away is probably not
4 going to be borne out. I have seen patients with
5 T counts of 800 who have cognitive impairment.
6 It's not clear whether is that HIV, is that the
7 pre-existing drug history, is that brain damage.
8 Most of the people we test, we don't have
9 base line data from five years before they were
10 infected. But even in the sample, with the
11 history of drug abuse, people did not show up to
12 have significant neurocognitive involvement until
13 they began to have more immunological decline.
14 Now, it seems to me that there is a
15 difference between screening for HIV and helping
16 people to create job performance screening. When
17 I'm flying on an airline, I would prefer to have
18 my pilot have to do a performance evaluation on
19 the plane than what he does on a paper test in
20 somebody's kitchen. He is not going to become
21 demented and fly. I'm not worried about that.
22 He might become drunk and fly; that I'm worried
23 about. Or he might have had a fight in the
24 morning with somebody who cares about him. That

1 I'm worried about. But I'm not worried about
2 acute dimentia. That's not how the process
3 works.
4 I'm much more concerned about jobs being
5 able to monitor peoples' performance according to
6 criteria that makes sense. Instead of drawing
7 HIV tests on school bus drivers, we should do
8 breatholizer admissions. That is a performance
9 monitor of something that is important. So the
10 test itself is in no way, I think, helpful in
11 discerning whether or not people have
12 consequences of HIV infection. I think the fact
13 that HIV is in the brain probably early on does
14 not mean that it's clinically relevant to
15 performance impairment.
16 So I would like to distinguish between
17 neurocognitive testing, not knowing what the base
18 line is, and also what we know about in terms of
19 performance criteria for people accomplishing
20 certain tasks. HIV testing doesn't accomplish
21 that.
22 CHAIRMAN ALLEN: That's very
23 helpful.
24 MR. GOLDMAN: You would agree that

1 in the context of paid blood donors, that would
2 be an appropriate employment screen?
3 DR. FORSTEIN: Absolutely. You
4 call it employment.
5 MR. GOLDMAN: If somebody is paid
6 for it.
7 DR. FORSTEIN: I think what we're
8 screening blood for is very different from
9 screening airline pilots to see if they could
10 fly. We are testing for the virus, not for job
11 performance.
12 CHAIRMAN ALLEN: I would like to
13 bring in Marc at this point. Thank you very
14 much, Marshall. I'm pleased you're going to be
15 able to be here through this conversation.
16 The Commissioners have talked to Marc
17 about something that we would hope to get out of
18 this day today is to looking at that kind of
19 continuum of care and the patterns of needs and
20 to look at this not in a compartmentalized
21 situation but to look at it as a whole entity of
22 this progression through the process from the
23 individual, perhaps, from the individual's point
24 of view and how that individual interacts with

1 the social structures. So it would be helpful
2 for us.
3 That's just a jumpoff point. What we
4 would like to come out of this with is to get an
5 overview and clear picture of this whole process
6 from the beginning to end, if possible. For
7 instance, one of the issues that came up when
8 Marshall was speaking was what about the anxiety
9 level of an individual, when does that override
10 the anxiety of finding out that they may be
11 positive? How do you interact with someone
12 through basic education to sensitize that
13 individual to the possible need to go for
14 testing? And sensitize the individual to what
15 the test means and so forth, as you are doing it
16 all the way to the final stages. So that's kind
17 of a hope.
18 Some other Commissioners may want to speak
19 up to some of their desires in this.
20 MR. GOLDMAN: The only thing in
21 that context, we ought to make it clear, as I
22 understand it, we're talking about the
23 psychosocial continuum, psychosocial needs, that
24 we're talking about the person who is, who we're

1 talking about being tested, who we're talking
2 about being treated. There may be a whole
3 different set of needs for the members of that
4 person's family, seronegative sexual partner of
5 that person, with other people in the community
6 with whom that person may deal, and a whole
7 different set of psychosocial issues.
8 I don't have any problem talking about
9 them, but we ought to be clear when we're talking
10 about psychosocial needs and concerns as to whose
11 psychosocial needs and concerns we're talking
12 about.
13 CHAIRMAN ALLEN: Okay. Any other
14 comments? Do you all have a clear goal or
15 desire? That would be helpful to us.
16 DR. ROBERTS: I thought we would
17 start with a slight expansion of what Kate
18 [Cauley] suggested, who is no longer with us, but
19 suggested yesterday toward the end of the session
20 where she talked about how testing was an
21 intermediary point in a continuum. And we had
22 been talking both about various outreach
23 mechanisms that brought people in to testing, and
24 various community education and prevention

1 efforts which were not necessarily tied to
2 testing.
3 And in keeping with what Don just said,
4 both for people who are positive, you find
5 medical and psychological, which we've just
6 talked about, and social and prevention sorts of
7 things, and for people who are not positive,
8 either contacts or individual prevention. And
9 Deborah Cotton yesterday talked about
10 particularly the continuum of medical care and at
11 what point it made sense to switch people among
12 various sites and circumstances of care.
13 I want to say two things I heard in our
14 conversation yesterday that I want to offer to
15 all of you as some feedback as we proceed this
16 morning. One, I sense some unwillingness for
17 some of you to disagree with each other. There
18 were some real disagreements, and interesting
19 ones yesterday, but there is a little bit of a
20 reluctance to disagree because there is the
21 Commission and here you are, and you're all
22 trying to influence them. And there is some
23 sense of wanting to maintain a united front in
24 the face of the Commission.

1 I want to urge you where you really
2 disagree to expose those disagreements to the
3 Commission because I think it will be more
4 helpful to them to see the variety of opinions
5 and perspectives in the room.
6 The other thing that I urge is, I think it
7 would be more helpful if we tried to stay more
8 focused on one thing at a time. I know it's very
9 tempting. There are eight things I want to say
10 to the Commission and I have air time, but I
11 think it would be more helpful to them if we stay
12 on one topic at the time because there's always
13 the possibility of written admissions and other
14 arenas in which you can submit your views on.
15 I have been told both that some people
16 feel that some people talk too much and they
17 haven't gotten enough air time, and other people,
18 including people who talk a lot, who feel I've
19 been too controlling and not letting them have
20 enough air time. We have a broad spectrum of
21 responses about how we ought to modify what we do
22 today.
23 I thought that just to begin, we could
24 start thinking about this continuum and begin to

1 talk about the question of which of these things
2 are we doing relatively well and badly. In terms
3 of providing -- and on this part here, we talked
4 about case management, team management, the fact
5 that this is a multifunctional set of
6 interventions and assistance that's needed all
7 the way from group support to finding people
8 money, whatever it is.
9 I wonder what peoples' reactions are as
10 you think about the spectrum of services that
11 people at different stages of the disease need
12 and different client groups need, as Don said.
13 What should the Commission hear about
14 where the real priorities are, the real
15 problems?
16 MS. GELFAND: I think one thing
17 that really needs to be taken a look at is the
18 fact that testing has always been separate and
19 apart from anything to the right of your little
20 squiggle there, separate from the medical, the
21 psychological, the social, whatever, separate
22 from the outreach and the education and
23 prevention, there has been this testing. And I
24 think that we really need to look at testing as

1 an entry point into that whole system to the
2 right and stop separating it out, stop separating
3 the services and the people who are doing it and
4 the agencies who are doing it.
5 I think the agencies can connect in a much
6 better way than they are in each city.
7 DR. ROBERTS: Say more about this
8 connection among agencies.
9 MS. GELFAND: My own personal
10 example is we are doing testing and beating our
11 heads against the wall because we can't outreach
12 to communities of color. I think it's a
13 wonderful idea because the AIDS Project is going
14 to be testing. Instead of our agency getting all
15 uptight about it being taken out of our hands, we
16 need to allow that to happen in different places
17 in the city and not just take it all on ourselves
18 to be the end all.
19 AIDS Project-Los Angeles is talking about
20 putting case managers in alternate test sites.
21 I'm not entirely sure I think this is a great
22 idea, but the idea of working with AIDS Project-
23 Los Angeles instead of against them or in
24 competition with them needs to be looked at. I

1 think that's what brought up the corroboration
2 effort.
3 DR. ROBERTS: I hear you saying
4 something that I heard some of yesterday that the
5 I thought we were sort of wandering around a
6 little bit; namely, that as the epidemic shifts,
7 the nature of the agencies and kinds of voluntary
8 groups that need to take the leads shift, and
9 that one agency that can function in a gay
10 community can't necessarily operate effectively
11 in communities of color.
12 MR. LEVI: We almost need something
13 added to that chart. I think what Jackie said is
14 really accurate, that we've dealt with one side
15 and not the other. But there is a reason why the
16 testing originally was placed outside the
17 traditional system. And it is both an obstacle
18 to people seeking testing, but it's also an
19 obstacle to people seeking the related care that
20 they need, and that is the insurance issue we
21 talked about, the issue of mandatory reporting,
22 the issue of partner notification, assuming all
23 those things were in place, which they are not,
24 on both sides of where testing is.

1 There are other obstacles that society,
2 government, the economy, or whatever, have placed
3 that prevent dealing with this issue in a
4 rational way. It is not irrational for someone
5 to seek testing outside of the care system if
6 they think they are going to lose their job or
7 their insurance or whatever. And so society or
8 the government or whatever needs to do something
9 to rationalize the process.
10 DR. ROBERTS: So if we are going to
11 satisfy Jackie's concern, there are other things
12 that need to be done to allow this to happen in
13 the real world.
14 MR. LEVI: Yes.
15 MS. DOMB: One thing I would add,
16 following that, in terms of what needs to be done
17 in the real world, in areas you have physicians
18 who would much prefer to send a patient to an ATS
19 program because they know they are incompetent in
20 it, they have no experience, they've had bad
21 experience, maybe they told someone over the
22 phone they had AIDS when they got a positive test
23 result. So testing definitely, I think, now is
24 an entry point to that entire system, but it's a

1 system that this area is not equipped.
2 Government has funded the ATS program but the
3 psychosocial medical case management parts of the
4 system are not; there, they are there but not
5 prepared for it.
6 CHAIRMAN ALLEN: Just a question
7 for you all. Should testing be an entry point?
8 MR. BATCHELOR: No.
9 CHAIRMAN ALLEN: I think that's
10 something we need to look at.
11 DR. ROBERTS: Could you be more
12 clear, Scott? Do you mean should testing
13 necessarily be an entry point or an optional
14 point?
15 CHAIRMAN ALLEN: Should it be an
16 instrument of entry into the system?
17 DR. ROBERTS: Jackie, do you want
18 to respond?
19 MS. GELFAND: Yes. Personally, if
20 we're going to have testing the way it exists
21 today, then it needs to be an entry point to a
22 system. I don't necessarily mean the big bad
23 boogeyman health care system, but obviously a
24 compassion at health care system. When I think

1 of it at my site, I give the test, I give the
2 positive test result, I have the luxury of being
3 able to take this client over to a nurse in my
4 AIDS clinic, turn them over, give them an
5 appointment and then take them upstairs to a
6 counseling department person who can deal with
7 their immediate crisis needs and hook them up
8 with a support group. And that is the kind of
9 system I'm talking about. It's sort of a
10 comprehensive kind of system as opposed to turn
11 them out to county USC Hospital, which is a scary
12 thought.
13 DR. ROBERTS: Somebody who said
14 no?
15 MR. BATCHELOR: I feel very
16 strongly. I think for most people testing is not
17 the entry. And the system to the right of the
18 squiggle is really the AIDS system, the AIDS care
19 system, very broadly defined.
20 I think most people with entry to the AIDS
21 system is public education. I think that should
22 be the entry point to the AIDS system. People
23 should not get tested as their first entry in
24 understanding what AIDS means to them

1 personally. In fact, few people do, only people
2 who give blood find out, women who give birth,
3 for instance. And, yet, most people choose to
4 get tested based on their understanding of AIDS
5 or their fear of AIDS, or their fear about their
6 own personal risk behaviors in the past.
7 MS. GELFAND: Can I respond for one
8 second? I think you're right in terms of
9 education, but I think most people enter the
10 system when they get sick. I think the majority
11 of people enter the system when they find
12 themselves in the emergency room at County
13 Hospital and not from the educational point or
14 not even from the testing system.
15 MR. BATCHELOR: I think Reverend
16 Allen's question was should that be the entry
17 point. That's why I say firmly it should not
18 be. As I say, the system we have now I don't
19 think works well. I think people are quite alone
20 when they find out -- the answer to your
21 question, Mr. Goldman, about why this is
22 different --
23 DR. ROBERTS: Could I interrupt?
24 We're all on a first name basis.

1 MR. BATCHELOR: The system is in
2 place to respond to peoples' needs after they are
3 tested are for the vast majority of people not
4 appropriate. The vast majority of people do not
5 have T-cells below 500 or below 200, the vast
6 majority. Medical interventions are irrelevant.
7 The vast majority of people are not willing to
8 face the social stigma, the political stigma, the
9 economic, the insurance, the medical and the
10 self-imposed stigma to tell other people that
11 they are HIV positive.
12 I got tested in 1984 as part of an NIH
13 project right after they discovered the virus. I
14 didn't tell a soul for several years; partly at
15 the beginning I didn't know anybody to tell. I
16 thought I was one of eleven in the country who
17 knew. It's taken me until last year to tell
18 people, five years to tell people. I feel
19 immensely better now, but I was facing death
20 every day for five years because there wasn't any
21 system in place. I've been getting better. My
22 T-cells are going up. I'm healty as can be. But
23 the system says I'm sick, I need medical
24 intervention, I'm crazy, but for the vast

1 majority of people it's not there.

2 In Boston, we don't have enough

3 intervention programs. Social support is very,

4 very important. It's only when you can tell

5 other people that you're positive that you can

6 really get that social support.

7 DR. ROBERTS: Thinking about this,

8 I hear you saying two things, and maybe we can

9 disentangle them and be helpful.

10 One thing I hear you saying is that it's

11 much better if people get contacted and enter

12 into the system out here as opposed to enter in

13 directly through the testing.

14 The other thing I heard you saying was

15 that particularly at the early stages of

16 infection you think that the social and

17 psychological dimensions are far more important

18 than the medical dimensions.

19 From your experience, would you say that

20 those are particularly unavailable? Is that what

21 I hear you saying? The social and psychological

22 assistance?

23 MR. BATCHELOR: Social, I mean,

24 there is virtually no social support outside of

1 AIDS service organizations. And the rare
2 physician who has got, you're not sick, the
3 physician doesn't need to see you. But to get a
4 physician is really helpful and caring is just
5 exceptionally wonderful. But the social support
6 is not there, the social stigma within any
7 community, gay, black, white, men, women, that's
8 irrelevant. There is no social support for
9 saying, Hi, I'm HIV positive, do you want to go
10 out for a date. That don't work.
11 DR. ST. JOHN: I think what Walter
12 is saying is very nice. And we addressed some of
13 this yesterday. We do not have a wellness-
14 oriented system; we have an illness-oriented
15 system. And it seems to show no tendency toward
16 any major, major change.
17 It would be nice if the first point of
18 entry was when you got up in the morning and you
19 felt really great and you said, gee, maybe I
20 should go in to see my health care provider so I
21 can tell him how great I feel so I can get
22 positive reinforcement. For most people,
23 regardless of socioeconomic status, they tend to
24 have their first entry into a system when they

1 feel bad.

2 DR. ROBERTS: I wonder if one of

3 the people from CDC could help us interpret the

4 data we saw yesterday about the question that

5 Jackie was raising and Ronald just raised. To

6 what extent now, leaving aside the issue of what

7 would be desirable, to what extent now do we

8 think people are coming in as a consequence,

9 Alan, of illness as opposed to outreach?

10 DR. HINMAN: Well, it's not only

11 one of, it is the one from CDC who is here

12 today.

13 DR. ROBERTS: I keep getting you

14 and Joe confused since he's wearing his uniform

15 still.

16 DR. HINMAN: Well, I had raised my

17 hand because I wanted to point out, as you talk

18 about entry into the system and testing as the

19 entry point into the system, that basically

20 focuses on the all alternate test site, the

21 anonymous test site; whereas, in the period

22 January 1988 through September 1989, publicly

23 funded testing, 60 percent of the testing was

24 carried out in sites other than alternate test

1 sites. 40 percent was in alternate test sites;
2 the remainder was carried out as a part of other
3 services that people were obtaining, the majority
4 of these being STD clinics attendees.
5 Again, this was not an issue of someone
6 deciding I want to go in and get tested and going
7 to an ATS site. This was primarily a person who
8 was in an STD clinic or family planning clinic or
9 some other setting who was offered the prospect
10 of testing and who decided to be tested.
11 I should say that in most of these
12 clinics, fewer than 50 percent of the people who
13 are talked to decide to be tested.
14 MR. LEVI: I have to ask a factual
15 question about that because --
16 DR. ROBERTS: Go ahead.
17 MR. LEVI: Alan, I have to ask a
18 factual follow-up because I completely believe
19 you that those statistics are true. The question
20 I have is was that driven by funding cycles? In
21 other words, did the funding made available to
22 alternative testing sites remain level or decline
23 in how states chose to use their testing and
24 counseling money while money was being pumped

1 into the STD system and other clinics to make
2 sure that the counseling and testing was
3 offered?
4 In other words, did this just happen or
5 was there a conscious decision at the CDC that we
6 wanted to shift some of the testing and,
7 therefore -- for example, did funds increase at
8 alternative testing sites?
9 DR. HINMAN: The answer is that
10 there was a conscious decision to try to extend
11 counseling and testing to sites other than
12 alternate testing.
13 MR. LEVI: So while it is accurate
14 to conclude that more and more testing was
15 occurring at these other sites, it is not
16 necessarily accurate to conclude that this
17 occurred because it's a better way of doing it or
18 that there was diminishing interest in
19 alternative testing sites.
20 MS. AFFOUMADO: I think we have to
21 understand how it was done because I think that
22 that also has to play into the psychological and
23 the social issues of this disease for the people
24 who go to STD clinics. In New York City, for

1 example, if somebody went to a public health
2 clinic to get tested for syphilis or gonorrhea
3 and they had a positive test for syphilis, it was
4 strongly suggested to the point of almost
5 coercion that they should get an HIV antibody
6 test because this positive syphilis pointed up
7 that they might have a life-threatening illness.
8 People who have tested positive for TB in
9 New York City have also had this strongly
10 suggested request made of them. Now you're
11 talking about people who are terrified of people
12 who may appear to know more than they do because
13 they are wearing white coats and little nurse's
14 caps in STD clinics, so they have gotten tested
15 with very poor counseling and very poor follow-
16 up.
17 And I think that this model now in New
18 York, for example, is being even further expanded
19 to look at the possibility of doing T-cell
20 testings in STD clinics because that's the
21 "appropriate" place to do this, and Pentamadine
22 and early diagnosis and treatment, which only
23 means AZT, and that's all it means. So we're
24 talking about this impact on the psychosocial and

1 the manner of which testing is suggested, in
2 quotes, and I think that that's a real important
3 issue that you have to understand.
4 DR. ROBERTS: So what I hear you
5 saying is that the notion of integrating testing
6 into the care system from your point of view
7 that's less important, mainly, whether it's
8 integrated or not, than how it's done; and that
9 doing it in one site or another doesn't guarantee
10 whether you really get client-centered care.
11 It's perfectly possible inside a health care
12 facility that's not AZT-oriented to do a really
13 bad job.
14 MS. AFFOUMADO: But you've got to
15 understand that STD clinics are not health care
16 models. I keep wanting to bring you back to this
17 because we are looking at this as a treatment
18 specific disease, and it is not treatment
19 specific. It has a wide, wide range of things
20 that have to be done for it.
21 And AZT, one more point, -- I'm very
22 scared that we are going to look for a cheap fix,
23 and this is not TB and it's not syphilis; it's
24 HIV.

1 One other real brief thing. When you
2 start talk about giving AZT to people who feel
3 healthy, then you also say that maybe they're
4 sick. And I think that maybe we have to look
5 again, going back to Marshall's excellent
6 psychosocial overview of the sense of telling
7 people that they have to swallow a pill which
8 then indicates to them that they are not healthy.
9 DR. ROBERTS: What I hear you
10 saying is that to provide medical intervention
11 without moving in the other dimensions, you
12 think, is very inappropriate. And you're not
13 convinced that the STD clinic is a cite that will
14 do anything other than move them down the medical
15 line.
16 MS. AFFOUMADO: They can't.
17 MR. DALTON: Several things on the
18 table, but it really has to do, I hear Alan
19 saying that 60 percent of the people, 70 percent
20 who know they are HIV positive found out through
21 publicly-funded testing sites.
22 DR. HINMAN: In the year, nine
23 months I talked about 60 percent of the testing
24 was done in sites other than ATS, but 50 percent

1 of positives during that period were found in
2 alternate testing sites.
3 MR. DALTON: In any event, what it
4 triggered in my mind, and the additional piece of
5 information in response to Jeff's question is
6 that through conscious choice backed up by
7 funding, people can funnel in the direction of
8 STD clinics, that raises the question of what
9 happens in STD clinics. Implicit in what Rona
10 said is it's her view that STD clinics do a less
11 good job of counseling or referral, of follow-
12 up.
13 I guess my question is what is the
14 experience of people around the table about the
15 relative provision of those kinds of services in
16 STD clinics as compared with alternate test
17 sites? My question for Alan is whether the
18 government in fact has minimum standards for any
19 of the above in terms of things like the amount
20 of time spent on counseling, the kind of things
21 covered in counseling, and whether those
22 standards are the same for STD clinics as for --
23 DR. ROBERTS: Alan, do you want to
24 start? Are there standards for the non-medical

1 aspects of care in these STD clinics and so on?

2 DR. HINMAN: The counseling, in

3 theory, should be comparable in alternate test

4 sites and in STD clinics. I cannot guarantee

5 that it is.

6 From the point of view of standards --

7 MR. DALTON: You say you can't

8 guarantee. Are you saying that there are steps

9 you could take that would tend to drive people in

10 that direction? Or that you in fact have taken

11 steps --

12 DR. HINMAN: We have guidelines for

13 training of counselors. We carry out training

14 sessions for counselors, and we train trainers

15 for counseling, both counselors in alternate test

16 sites, in STD clinics and other sites. So we are

17 attempting to assure that counseling is

18 comparable.

19 In practice, I cannot guarantee that it

20 is. I do not have basically a counseling cop in

21 every alternate test site or in every STD

22 clinic. I can say that one of the problems in

23 trying to bring counseling and testing into STD

24 clinics and, particularly, into drug treatment

1 clinics, for example, is that most of these
2 clinics are already overburdened, as was
3 mentioned about mental health facilities, and
4 particularly in IV drug treatment centers where
5 they know there is a long waiting line of people
6 to get into the program. There may not be a lot
7 of enthusiasm about devoting space. We do not
8 promote that the IV drug treatment center
9 employees give the time, but they may not feel
10 they have the space to give. So there may not be
11 as much as enthusiasm.
12 MR. DALTON: The conscious decision
13 to tilt testing in the direction of STD clinics,
14 drug treatment sites and the like as against
15 ATSs, was that premised on the assumption that
16 the counseling and referral services would be the
17 same in both sites? Was there a premise in
18 judgment about the capacity of those institutions
19 to be able to do what you want them to do?
20 DR. HINMAN: The premise was to try
21 to bring counseling and testing to people who
22 might benefit and those who might be at greater
23 risk of being infected. The dynamics of who goes
24 to an alternate test site versus being tested in

1 some other site are difficult to really manage.

2 We have seen, for example, in persons

3 tested in alternate test sites a declining

4 positivity rate since the alternate test sites

5 were first established reflecting presumably the

6 fact that the test sites that were initially put

7 in place, the people who were at greatest risk of

8 being infected or who were most concerned about

9 being infected went to use those sites. And over

10 time, this is, the positivity rate declined and

11 more or less stabilized, reflecting presumably,

12 then, a not exhaustion, but at least a completion

13 of some of the backlog of concerned infected

14 individuals.

15 MR. LEVI: You mentioned yesterday,

16 if you could just remind us, yesterday the return

17 rate for HIV test results and ATSs versus other

18 sites because I believe there was a significant

19 difference.

20 DR. HINMAN: There is. The return

21 rate for ATS sites is about 76 percent. And it

22 varies in other testing sites as low as 30 to 40

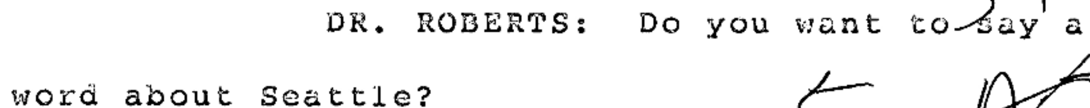
23 percent.

24 MR. LEVI: Do you think that has

1 something to do with STD clinics being so
2 overwhelmed you literally have to spend the
3 entire day there before you can get an
4 appointment to see someone? Some inner city
5 sites are saying if you're not there by 9:30
6 you're not going to get in that day.
7 DR. HINMAN: That may be a part of
8 it. I think, also, there is a different
9 motivation. The person who goes to an alternate
10 test site is saying on the face of it, I want to
11 get tested and I want to find out about the
12 results; whereas, the person who is in an STD
13 clinic because of gonorrhea may not be as
14 enthusiastic. We see this obviously with lower
15 test rates of the people who are --
16 DR. ROBERTS: Could we get some
17 experience from other people around the country?
18 Rona offered us her view about the empirical
19 comparison. Jackie, do you want to say something
20 or Jill?
21 MS. STRAWN: Having worked in an
22 alternative test site, when the shift was
23 happening from focusing on anonymous testing to
24 doing testing in the STD clinics, it was my

1 experience and most of the AIDS community
2 experience that what they were interested in was
3 testing, not testing and counseling. So, in
4 fact, the additional responsibilities of the STD
5 staff who were hired for one thing and trained
6 for one thing suddenly became, and you also have
7 to do AIDS counseling and testing, in addition.
8 We haven't talked yet about what is
9 counseling, and that's a whole large
10 conversation; and then also what kind of people
11 can do this counseling well. And it often is not
12 the people that have been hired to do something
13 else. So a lot of testing has gotten done, but I
14 really wonder how much counseling has gotten
15 done.
16 MS. DOMB: That's been the case in
17 Massachusetts. When I started working in the
18 alternative test site in western Massachusetts, I
19 was called to do counseling in the STD clinic
20 because the nurses wouldn't do it. Boston knew
21 that even if they said they were doing it, they
22 probably weren't. Massachusetts did, though,
23 started recruiting people for the STD/HIV
24 component from the ATS program, so that they were

1 getting the people who were enthusiastic about
2 counseling about the HIV antibody test into the
3 STD clinics.
4 I think your point about who applies for
5 the STD job and who applies for ATS job is key.
6 People who are doing STD don't want to be doing
7 HIV counseling.
8 DR. ROBERTS: Do you want to say a
9 word about Seattle?



10 DR. O'NEILL: I had the experience
11 of working at the same time as a testing
12 counselor at an alternative test site as well as
13 attending in the sexually-transmitted disease
14 clinic at the County Hospital. I was doing these
15 things simultaneously.
16 I think one of the things that strikes me,
17 it may be only specific to Seattle, not only are
18 there different populations of patients using the
19 facilities, but different populations of
20 providers working in the facilities. The
21 motivation level, both among the users as well as
22 among the people working there, was very much
23 more oriented towards counseling and support, of
24 which a piece of that was the test.

1 There was a different feeling at the STD
2 clinic in terms of, I think you just articulated
3 it very well, saying this is one more thing to be
4 done on a long checklist of things needed to be
5 done as an appropriate workup of a sexually-
6 transmitted disease.
7 CHAIRMAN ALLEN: I have something
8 to say about that. We have kind of tried to stay
9 away from the racism and the prejudice, but do
10 you find or is there a possibility of making the
11 hypothesis that there is a greater potential when
12 there is an individual that looks like you, that
13 perhaps you're from the community that that's
14 from, to have more empathy and that greater sense
15 of counseling enthusiasm for the job, and in an
16 STD clinic where someone comes in that is
17 impoverished, that you may not feel that much
18 empathy for? There seems to be a big
19 difference.
20 As we see the shift, maybe we should start
21 talking about the indiginous type of needs of the
22 community, to have folks that are sensitive to
23 your own plight. So you're talking about the
24 difference, I think that needs to be taken into

1 account. And we also need to consider the
2 expanding, not shifting, but the expanding needs.
3 DR. O'NEILL: I think a way of
4 putting it in a positive light is saying what
5 worked well about the alternative test site was
6 precisely that sensitivity towards the community,
7 at least at the time I was working there, was
8 directed towards the major users of the facility.
9 MR. SANCHEZ: I just want to say
10 very briefly what my experience has been in New
11 York, and that is that the STDs are located in
12 poor communities and in communities of people of
13 color. The history of STDs is very poor. The
14 counseling is inadequate. They are receiving
15 five minutes of pre-test counseling, five
16 minutes. That is what people are getting in New
17 York in STDs. They are receiving pressure by
18 counselors to report their partners.
19 So it's a major concern to me, when I hear
20 the promoting of STDs and the volume of people
21 who are being tested in those clinics. And I
22 just hope that it's not just discussion, but that
23 something is actually done to upgrade the quality
24 of services and treatment.

1 MR. WHITE: One of the things that
2 we are experiencing, and I think, if I'm correct,
3 all testing has gone under STD, is that we, in
4 January, were told we were going to be put under
5 a quota system of 160 per week, which means then
6 that we have to meet this quota to retain our
7 funding. We are resisting that.
8 MS. DIAZ: What funding?
9 MR. WHITE: Our federal funding.
10 They are saying that we are spending too much
11 time being empathetic. You're laughing, but this
12 is what we have actually been told because we
13 want to spend time with our clients, making sure
14 they understand what's going on with them. What
15 are we supposed to do? Because the STDs are
16 doing that, and we are supposed to be the
17 alternative to them, and you're taking that from
18 the community and from the people who really need
19 it.
20 MS. AFFOUMADO: You could even
21 extend that to the public health clinics who have
22 certain productivity levels to meet utilization,
23 and it's the same thing. They lose funding for
24 that, too.

1 CHAIRMAN ALLEN: I have a question
2 for Bob. Is there a waiting list that you have?
3 MR. WHITE: No.
4 CHAIRMAN ALLEN: So that's not an
5 issue?
6 MR. WHITE: It's not an issue.
7 What's happening is they are saying we are not
8 utilizing the money appropriately because the
9 numbers are not representing what they want, the
10 number of clients that we are interacting with to
11 represent for the amount of money they are giving
12 us.
13 CHAIRMAN ALLEN: That was my
14 question.
15 DR. ROBERTS: Alvin?
16 DR. NOVICK: I think this reflects
17 something that I said yesterday, the "called"
18 people as opposed to the people who are forced to
19 provide services. So I want to go further. We
20 are hearing over and over again the undercurrent
21 that we don't have enough people that are
22 properly trained in both the factual stuff and
23 the sensitivity and the depth and the compassion,
24 the whole set, and that training is lacking. I

1 think it's what we're saying is lacking in the
2 system; that it doesn't have the proper
3 counselors. Jill spoke of that. The same lack
4 is in the other sets.
5 We had the little fight about doctors. We
6 don't have training systems in America for HIV.
7 The first such college program, as far as
8 we know, is going to be implemented in
9 Connecticut in the fall. It's going to offer a
10 certificate in HIV care at the graduate level for
11 community workers and for social workers and
12 others. And we need those because without them
13 we either depend on the identified committed
14 people, or we have STD employees who couldn't
15 care less.
16 So we have to have a new set of STD
17 employees who get into that because they're
18 trained and have a certificate.
19 DR. ROBERTS: I just want to
20 suggest, Alvin, I heard a fairly complicated
21 description of the problem that was certainly not
22 just training; that is, there is the issue of
23 self selection and the issue of funding and
24 productivity standards as well as the issue of

1 training that determines the quality. So I
2 didn't hear that it's not just the training.
3 DR. NOVICK: But we do not have
4 enough trained people in America to provide the
5 services we require.
6 MS. GELFAND: I want to say that in
7 the California example, when I think of STD
8 antibody testing and alternate test site antibody
9 testing, it's the same in my mind. The reason is
10 because there is no one in an STD clinic that has
11 not been given the same counselor training that
12 an alternative test site counselor has gone
13 through, or they won't be doing training. It's
14 the same that goes on in any test site, whether
15 in our STD clinics or confidential test sites, as
16 opposed to an anonymous test sites. There is an
17 extensive training.
18 DR. NOVICK: That's three days of
19 training, trivial training.
20 MS. GELFAND: But ongoing three or
21 four times a year. It is ongoing.
22 DR. NOVICK: It's imposed on them,
23 too, rather than voluntary.
24 DR. ROBERTS: What I hear, there is

1 no reason for us to have disagreements based on
2 geographic variety because what I hear is that
3 there is a lot of geographic variety; that the
4 relative effectiveness of different sites in
5 different parts of the country as a function of
6 funding and productivity is very different.
7 You talked about how counselors in STD
8 sites were selected from the alternate test sites
9 and they were self-selected and so on. So there
10 is no need to come to a consensus because America
11 is a big country, and it's three thousand miles.
12 MR. GOLDMAN: The discussion has
13 been interesting, but let's go back to Scott
14 saying, he started off asking whether or not
15 testing should be an entry point. Harlon asked a
16 question of Doctor Hinman relative to whether or
17 not the decision to shift was based upon some
18 determination that at one point was a better
19 entry point than another point. And Alan's
20 response that the issue of entry point had
21 nothing to do with it, that it was purely
22 epidimiological, and what happened to the person
23 that was tested in terms of their care afterward
24 was really an irrelevant care in the process.

1 DR. HINMAN: I hope I did not say
2 that.
3 MR. GOLDMAN: Well, I don't know
4 what happened to the person afterwards, but in
5 terms of using that criteria in terms of which
6 was the most important entry point into the
7 health care delivery system, then I don't think
8 that most of the people who deal in terms of
9 setting up programs for HIV testing other than
10 those in the field look at it in terms of what's
11 the most effective point of getting somebody
12 entered into the health care delivery system.
13 There are a whole bunch of other issues
14 involved, largely involving issues of protection
15 of others and modifying sexual behaviors. And if
16 somebody went crazy but was impotent as part of
17 that process, that would be deemed a success.
18 MR. DALTON: Could you say that
19 again?
20 MR. GOLDMAN: If as a result of
21 testing somebody became crazy but became impotent
22 --
23 CHAIRMAN ALLEN: Physically.
24 MR. GOLDMAN: Physically impotent,

1 that that would be deemed a public health
2 success.
3 DR. ROBERTS: Whose position are
4 you characterizing as that? What I didn't
5 understand and I think other people don't, you
6 are saying some people take the following
7 position. Who is the some people?
8 MR. GOLDMAN: I think those who are
9 involved in public policy who have nothing to do
10 with AIDS or HIV infection, and our state
11 legislators and other federal and state
12 government in many respects.
13 DR. ST. JOHN: I disagree because I
14 work at that level, and I know a lot of people
15 who are very concerned about these kinds of
16 issues. So I disagree with you completely.
17 MR. GOLDMAN: You disagree that --
18 DR. ST. JOHN: You're outlining a
19 whole position that sounds very cold, very
20 scientific, and doesn't take into account human
21 values. I don't think that's true.
22 MR. LEVI: But think about it,
23 Ronald. He may have put it in an extreme form.
24 MR. GOLDMAN: I did.

1 MR. LEVI: Which is useful because
2 it was provocative.
3 DR. ST. JOHN: It provoked me.
4 MR. LEVI: But think about it.
5 Within the CDC alone, the "America Responds To
6 AIDS" program, as Eunice pointed out before, is
7 going to be encouraging people to be tested.
8 Yet, within the CDC, has a corrolation been made
9 between increasing the demand for testing and
10 expanding the level of funding dramatically for
11 alternative testing sites? No. And that is
12 within, well, the budget numbers don't reflect
13 it.
14 DR. ST. JOHN: CDC doesn't expand
15 funding.
16 MR. LEVI: Or the Public Health
17 Service did not request sufficiently larger
18 increments of funding for testing and counseling
19 to reflect the demand that their program is going
20 to create. The numbers don't lie.
21 So within one agency, you already have a
22 dissidence. You have one message being put out
23 to create a demand and no commitment of resources
24 to meet that demand.

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1 DR. ROBERTS: Excuse me one
2 second. The really Machiavellian view is that by
3 testing a lot of people who are then positive,
4 you will then create the demand for service.
5 MR. LEVI: No, not even meeting the
6 testing demand.
7 MS. BYRNES: I wouldn't just blame
8 the CDC. The federal government does this over
9 and over again. Money goes into the treatment
10 and there are no structures or slots to be
11 provided.
12 MR. LEVI: I'm just saying --
13 DR. ROBERTS: You're saying this is
14 the characteristic inefficiency of the federal
15 government.
16 MR. LEVI: You work for NAPO, which
17 is supposed to be coordinating all the different
18 agencies. Let's say CDC did what it should have
19 done, where are the additional funds at HRSA to
20 support the mental health services and the care
21 services and all the other things that people are
22 going to need? They are not there.
23 In fact, when you look at the care budget
24 proposed for fiscal 1991, it is dramatically

1 lower rather than higher for those services.

2 DR. ROBERTS: Let's let Alan have a

3 chance to respond.

4 DR. HINMAN: I would just remind

5 everyone briefly about how budgets are prepared

6 and submitted, just to reflect a little bit. At

7 the programatic level, there are people who are

8 advocates as strong as anyone in this room or in

9 any other room who propose what they think

10 absolutely must be done. There are people in

11 similar positions for every range of activity at

12 CDC. These people each put together a proposal

13 for what they think needs to be done and how much

14 it would take to do it.

15 These are then passed to the next level.

16 The next level looks at all of these great ideas

17 and says there is no way in hell all of that

18 money is going to be available. So some choices

19 are made at that point as to things that might

20 not be requested at all, or what level. This

21 goes to the next level and next level and finally

22 gets to the CDC level.

23 CDC decides based on indications they have

24 gotten from the Office of Management and Budget

1 and indications they have got to read my lips
2 about whether there is likely to be any increased
3 revenues available, and make some choices as to
4 what it will propose be recommended for the
5 Public Health Service.
6 This then goes to the Public Health
7 Service where the Secretary is trying to decide
8 between the request from CDC, request from NIH,
9 et cetera, and makes some choices, submits this
10 to the Department. The Secretary decides what he
11 thinks, given, again, the same budget deficit
12 targets and OMB targets, what is likely to be
13 saleable, and this gets sent to the Office of
14 Management and Budget, which has the final cut.
15 There are appeals back and forth at each
16 one of these levels. These then end up in one
17 way or another in the President's budget
18 submission to Congress.
19 Now, what the people at the working level
20 think is required to carry out X program, and
21 what appears in the Presidential budget
22 submission to Congress may have very little
23 relation. I think one has to recognize that this
24 is not at any stage a unilateral decision; it is

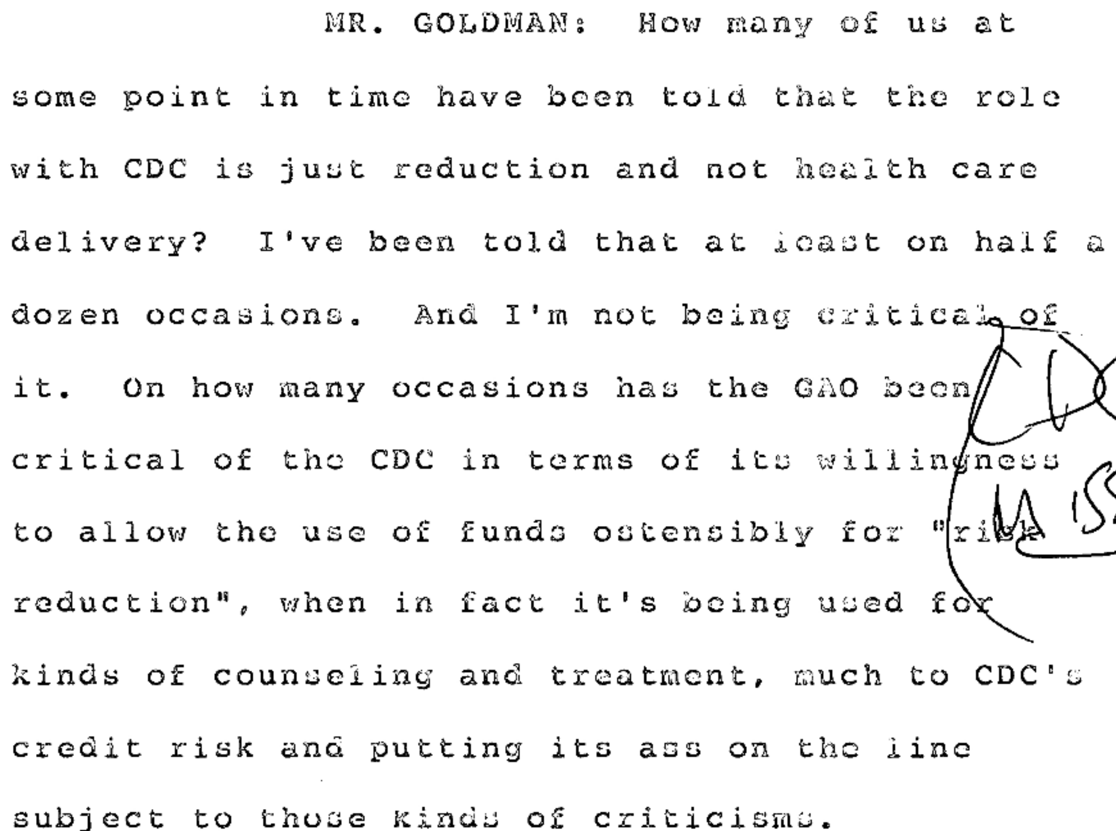
1 influenced by Congress, the general economy, the
2 administration, et cetera.
3 DR. ROBERTS: Alan, what would you
4 say, though, leaving aside the question of who is
5 responsible and one of the problems with the
6 budget system is that --
7 DR. HINMAN: We are all
8 responsible.
9 DR. ROBERTS: But what I heard the
10 thrust of Jeff's substantive point was the
11 publicity program and the budget requests are
12 conceptually and logically inconsistent,
13 regardless of who has produced the
14 inconsistency. That I heard, and I wondered how
15 you respond to that point as opposed to the
16 question of whether its CDC's fault or the
17 Secretary's fault.
18 What do you say to that point? You can
19 take a pass, if you wish.
20 DR. HINMAN: I would say that there
21 is some tension between those goals. But I also
22 have to say that it is unlikely that additional
23 support will be provided by Congress in absence
24 of clear demand.

1 DR. ST. JOHN: I know if you look
2 in the fiscal '90 budget, the 1.9 billion, that's
3 not what came up through the system. The request
4 that came up was somewhere between 2 and a half
5 to 3 billion dollars.
6 CHAIRMAN ALLEN: Just a couple of
7 comments. Clearly, the walk doesn't match the
8 talk when it comes to the advertising of early
9 intervention and the resources there. And that
10 is a big concern we have.
11 I would also like to take up for the
12 public health votes in that I know some people
13 that are anguishing over that aspect right now,
14 three of whom are right here. And it is a
15 terrible situation to be in.
16 The concern that I have is who is testing
17 really for? Is it for the society or is it for
18 the individual? And I think the testing was born
19 out of protection of the blood and it has
20 continued on in that mentality of the protection
21 issue.
22 And we have added on the sense, well, now
23 it can help the individual but I'm not so sure.
24 And that's something I'm struggling with is who

1 is it for. We've talked about the political
2 will, and this is part of the sociological
3 phenomenon; it runs deeper than that. It's the
4 capacity for compassion that we have as a
5 society. And I don't think we care. I don't
6 think as a society we care. So we are asking
7 people, we don't have that sense of compassion.
8 So it's not just the people at Public
9 Health Service; it's the people that vote, the
10 people that are out that simply don't care.
11 That's what disturbs me. If we want to do some
12 educating, we can't negate to the need for
13 general education for sensitivity to the issues
14 and the tragedy that is happening on a collective
15 sense. But I am just very concerned that we are
16 walking down this road with a pack of lies.
17 DR. AMARO: I am Hortensia Amaro
18 and I am at the Boston University School of
19 Public Health and on the staff at Boston City
20 Hospital.
21 I think the whole issue of testing is
22 really irrelevant when we have no system for any
23 kind of continuum of care. The women that I work
24 with, we have a project here within the NIDA

1 community-based prevention programs targeted at
2 pregnant women at high risk of infection. The
3 question of whether testing should be the entry
4 point for medical care is really irrelevant for
5 this group of women because these women are
6 totally disconnected from any kind of health
7 care. Testing is not going to be the entry point
8 for them. There is going to have to be a lot of
9 outreach and education before they will get to
10 the point of testing, and they are going to need
11 a lot of support.
12 A lot of these women are homeless, don't
13 have access to drug treatment, have a whole set
14 of issues around child welfare concerns. Unless
15 those issues are addressed, they will never get
16 to a point of considering testing. In fact, if
17 they do get tested, they probably, it will
18 probably be of no benefit to them because the
19 connection between that and the kind of services,
20 the level of services they need doesn't exist.
21 So I really want to support, you said "the
22 walk doesn't fit the talk", because we continue
23 to focus on testing instead of on how can we set
24 up a continuum of care. A whole set of services

1 that will really connect people to the services
2 that they need, and I really would hope that we
3 could focus this discussion more on that than on
4 whether testing should be in STD clinics or in
5 alternative testing sites because I think for
6 some populations, the framing of the issue in
7 that way is irrelevant. It doesn't get to what
8 they are facing as a barrier.
9 DR. ROBERTS: Don?
10 MR. GOLDMAN: How many of us at
11 some point in time have been told that the role
12 with CDC is just reduction and not health care
13 delivery? I've been told that at least on half a
14 dozen occasions. And I'm not being critical of
15 it. On how many occasions has the GAO been
16 critical of the CDC in terms of its willingness
17 to allow the use of funds ostensibly for "risk
18 reduction", when in fact it's being used for
19 kinds of counseling and treatment, much to CDC's
20 credit risk and putting its ass on the line
21 subject to those kinds of criticisms.



22 So all I'm trying to say is that here we
23 are people who are involved in HIV health care
24 delivery, and there are a lot of people out there

1 who have different agendas other than HIV health
2 care delivery in mind. And to talk in terms of
3 that is the agenda and that is the only purpose
4 of testing and testing is an entry into the
5 health care delivery system, therefore we are
6 talking about the health care delivery system as
7 a form of masturbation.
8 DR. ROBERTS: Marshall?
9 DR. FORSTEIN: I agree, underlying
10 my premise of why testing becomes the lightening
11 rod, I agree with Hortensia, testing is the least
12 common denominator of where money begins to make
13 sense because you can hire people, do a service,
14 measure what you've done. But there is a magical
15 thought by the government underlying all of this
16 that if you test people and you tell them that
17 they are positive or negative, people will do the
18 right thing. What this means is that people will
19 stop sharing needles and stop having sex. That's
20 the most primitive psychology underneath why we
21 want to test people.
22 We want to believe fundamentally, although
23 there is no data in any scientific way that
24 supports this, that if you tell people they are

1 positive they will stop doing what we don't want
2 them to be doing. If they find out they are
3 negative, they will avoid getting into trouble.
4 We have this unbelievably primitive and magical
5 belief that people always do what's best for
6 them.
7 MS. AFFOUMADO: "Just say no".
8 DR. FORSTEIN: That's why testing
9 sparks the lightening rod because to fund a
10 program which really speaks to the needs of
11 divergent changing communities is much more
12 expensive and much more complicated in its
13 design.
14 MS. AFFOUMADO: And you have to
15 care to do it. And you talk about creating
16 demand, by your advertising, there has been a
17 demand for health care services in this country
18 since the Sixties, since the Seventies. The
19 reason we have a health care crisis in New York
20 City and every other urban center in the United
21 States is because the Feds and other public
22 agencies have pulled apart the primary care
23 system in this country that we fought so hard to
24 put together in the Sixties and Seventies, and

1 all of a sudden it's been pulled out from under
2 us.
3 So of course we don't have a health care
4 system. We don't have anything to build on
5 anymore, it's been so completely dismantled by
6 the funding structures.
7 DR. ROBERTS: One of the
8 interesting themes that Marshall mentioned and
9 Bob mentioned because I want to raise it briefly
10 is this whole question of the pressure of
11 managers to find measurable outputs in the use of
12 productivity standards and what that does to the
13 quality of care. At some point, it seems to me,
14 it's at least worth people thinking about what an
15 alternative to that mentality as a control and
16 management system is. It seems to me that is a
17 serious problem if one is going to advocate
18 complex community-based services. There will
19 always be a GAO and there will always be an OMB
20 looking over peoples' shoulders with regard to
21 the question of productivity and quality and so
22 on. And there is, I think, a history of
23 suspicion of community-based organizations with
24 regard to those sorts of issues.

1 So at some point I would be really
2 interested in having people who are on the front
3 lines talk about their experience and how to
4 respond to those kinds of pressures.
5 We have talked a lot about this squiggle.
6 And to go back to it, Marshall talked a lot about
7 the psychological aspects. Hortensia started to
8 talk about the social aspects, about housing and
9 homelessness, for example.
10 In terms of the populations that we are
11 discussing, what are the key social aspects
12 because this is psychosocial; it's not just
13 mental health and psychological. Where are the
14 big gaps in terms of social services?
15 DR. FORSTEIN: I will give you one
16 example which we are dealing with in Cambridge
17 very concretely. For a person who is
18 undocumented to go to the ATS to get results of
19 the test is safer to come to an STD clinic who
20 then documents and opens up a medical chart and
21 the person becomes vulnerable to issues around
22 documentation, deportation, so forth. The
23 medical care system doesn't have a way to get
24 people from the ATS into medical treatment unless

1 we can in a sense subvert all of the structures
2 which would require things like recording,
3 contact tracing, that kind of stuff to the
4 partners.
5 That's one example of how the difference
6 between testing and different sites can mean
7 something different from different people.
8 People who have addictive behaviors,
9 people who hold jobs that are sensitive, are
10 unlikely to go to places whereby identifying
11 themselves as a risk for HIV then cascades a
12 whole series of different things, like getting
13 people homes, people losing their jobs, losing
14 Medicaid, being eligible for Medicaid.
15 DR. AMARO: I will tell you about
16 an example of the pregnant women we are working
17 with. We have women coming in, some of who are
18 seropositive, some of whom are at high risk, they
19 are pregnant. Through the course of education,
20 we talked to them about, we counseled them about
21 testing, and they may or may not get tested. But
22 we've had women who test positive. They are
23 homeless. We can't get them into any shelters
24 because shelters don't take people who are

1 actively using drugs. We even have some women on
2 methadone who won't be accepted into shelters.
3 If a woman comes in and find out she is
4 positive and if as part of her behavior change
5 effort decides she wants to get into treatment,
6 we can't get her into treatment. She then finds
7 herself homeless, still using drugs, goes to
8 deliver, and a 51(A) will be filed because she is
9 still using drugs and because she may not have a
10 place to take her child. So chances are her
11 child will be taken away from her.
12 Now that she doesn't have a child maybe
13 she has a better shot of getting into treatment
14 because she's not pregnant, but even then the
15 beds are limited. So I think there are obstacles
16 for different groups of people, and the
17 particular population I'm talking about,
18 treatment for women, especially, is very
19 difficult. For pregnant women it's almost
20 non-existent.
21 So I think drug treatment and housing,
22 shelter, and also for women there are child care
23 issues that come into play when women are
24 infected or begin to get ill.

1 CHAIRMAN ALLEN: Let me follow up
2 on that. If you're saying there is a potential
3 for the woman to lose her child or have the child
4 taken away, and presumably since we don't know
5 the positivity of the child, what happens in the
6 progression of the child?
7 DR. AMARO: When a woman delivers?
8 CHAIRMAN ALLEN: Yes.
9 DR. AMARO: Well, if there is an
10 investigation, then there is some assessment made
11 by the social workers in charge, whether this
12 person is able to take care of the child or not,
13 whether they are able to find a home for her or
14 some kind of shelter. If not, the child will be
15 put into foster care.
16 Sometimes at a later point, that whole
17 situation will be reassessed. But a lot of the
18 times, these women lose their kids and are not
19 able, sometimes a lot of them never regain
20 custody again. Some of them are able to regain
21 custody after they have been through treatment
22 and are able to show that in fact they are able
23 to take care of the kids and their lives have
24 stabilized. Because there are so many barriers

1 for them to get into treatment and for their
2 lives to stabilize, that becomes a really
3 difficult thing to achieve.
4 MR. SANCHEZ: May I just say that
5 at the Commission we have had cases and
6 situations where we have had to intervene on
7 behalf of women who are HIV positive, we have had
8 to educate the judges, basically, and inform them
9 of their violating the human rights law, just
10 based on the fact of the woman being HIV
11 positive, not being symptomatic or to the
12 progression of the disease, just the fact that
13 she is HIV positive. They have been real close
14 to special services for children taking the child
15 away from the mother.
16 DR. AMARO: I want to add one
17 thing. That is even to get women to get tested,
18 to get them to a point to where they want to or
19 are ready to get tested takes an ongoing
20 relationship, developing a relationship of
21 rapport and trust with the AIDS or health
22 educator that is part of the program. So that a
23 lot of the women will come in wanting AIDS
24 education, thinking they might be positive, but

1 they will not want to be tested until three or
2 four or six months down the line after they
3 really have a sense of trust.
4 DR. ROBERTS: This will be a good
5 time to take a break.
6 CHAIRMAN ALLEN: I would like to
7 make one announcement. I know there's been some
8 frustration because you want to speak. If you
9 have something that you would like to share with
10 us, you can put it in written form and give it to
11 us. That will not be lost. So don't feel like
12 this is your only shot. We do want to hear from
13 you.
14 (Recessed at 11:15 a.m.)
15 (Resumed at 11:35 a.m.)
16 DR. ROBERTS: During the break,
17 Larry Kessler said to me that he thought there
18 were some other aspects of this list of social
19 problems and needed social services that we
20 hadn't yet addressed. I asked him if he would
21 lead us off at this point and help us as to this
22 list.
23 MR. KESSLER: One of the things
24 that occurred to me in terms of talking the walk

1 and so on is that it hasn't come up here a lot,
2 but I know it's in the minds of everyone, but I
3 think for the record it would be good to state.
4 When we talk about access issues, that certain
5 groups who are considered in need of the test or
6 certainly in need of medical care and so on, have
7 greater access to things like crack, cocaine,
8 marijuana, ice, than they do to AZT and
9 aerosolized Pentamadine, and other things that
10 would be part of the continuum of care. And when
11 we butt that up against the kind of plan, the
12 Bush-Bennett drug plan, for instance, which
13 hardly mentions AIDS and doesn't deal with the
14 intersection of the two epidemics of addiction,
15 we have a problem. It's more than just no drug
16 treatment; it's easy access to some of the other
17 things that lead to drug addiction.
18 It easily moves into the whole question of
19 crime prevention and so on. But also, I think,
20 on the flip side talks about the legalization
21 issue and, again, the whole priorities of where
22 we put our money and what we invest in. And
23 we're more interested in investing in prisons
24 than we are in neighborhood health centers.

1 We're more interested in investing in helicopters
2 and security forces at borders than breaking down
3 the barriers that keep people from understanding
4 that AZT or AP is available or should be
5 available.
6 Hortensia reminded me of some of the
7 studies that came out recently that show quite
8 clearly that people of color and the poor have a
9 different longevity rate after diagnosis than
10 those who live on the other side of town or have
11 access to insurance.
12 But in the mix of that are all of the
13 other things that are enabling, that are
14 tempting, that contribute to the deterioration of
15 one's health, the social fabric, and so on. And
16 that piece, I think, just needs to be on the
17 table so we pay attention to that; specifically,
18 in addition to things like poverty and
19 unemployment. But the whole drug phenomenon is
20 out of control, and we need to look at that when
21 we're talking about controlling AIDS; that it is
22 a public health issue, not a criminal issue.
23 MS. DOMB: I think that's
24 interesting because driving in this morning they

1 were talking about the Summit and the South
2 American issue. South America looks at it as a
3 drug issue. The United States looks at it as a
4 law enforcement issue. I was saying what
5 happened to health in that whole discussion. I
6 think that trickles down to how we don't fund
7 programs that are accessible and available to
8 people not only in the cities but in non-cities
9 as well.
10 DR. ROBERTS: Mindy, I just want to
11 push you and push Larry a little bit on this
12 question because I think after lunch we're going
13 to want to talk a little bit more about the
14 funding issue. But at this point, it does seem
15 to me that we at least have to think about the
16 question of priority setting, admitting that not
17 all the money is going to be available out of any
18 budget process that we would like. And where
19 would you, if you had an extra $10 million, this
20 is the easy form of the question. The nasty form
21 of the question is where would you take $10
22 million?
23 MS. AFFOUMADO: The first question
24 is who would give it to her?

1 DR. ROBERTS: William Bennett gives
2 her $10 million. Seriously, what would your
3 priorities be about where we ought to be spending
4 additional monies?
5 MS. DOMB: The first one is
6 treatment on demand.
7 MR. GOLDMAN: For drugs, before
8 AZT?
9 MS. DOMB: Drug treatment,
10 rehabilitation programs, before AZT, definitely.
11 In fact, where I'm from in Pittsfield, the
12 physicians who are administering AZT to drug
13 users are finding that drug users are having
14 actually a harder time taking AZT. They are
15 having a harder time taking the treatment, and
16 it's also ruining their recovery. They don't
17 quite understand why that's happening.
18 MR. LEVI: Because no one has done
19 the clinical trials because they exclude people
20 who are active.
21 MS. DOMB: And they don't have the
22 necessary psychosocial supports that are
23 necessary for taking the pill. So I think
24 treatment on demand.

1 MR. GOLDMAN: Why is that more
2 important than providing housing for people with
3 AIDS that are homeless?
4 MS. DOMB: Because I'm using $10
5 million specifically to deal with drugs. Bennett
6 gave me the money. I mean, granted, it's always
7 hard to make a priority, and who is more needy is
8 probably the toughest decisions that people have
9 to make. But now I think IV drug users are
10 leading the fight in trying to get some kind of
11 handle on the epidemic and it has to address some
12 kind of issues in drug treatment. If we don't,
13 then we are basically putting up our whole finger
14 to that whole population and saying you are
15 dispensable, you don't have a lobby group we can
16 listen to; goodbye, see you later.
17 MR. GOLDMAN: But people with IV
18 drug use, large portions of those people may not
19 in fact be infected with HIV.
20 MS. DOMB: They are all at risk.
21 You look at a place like Pittsfield,
22 Massachusetts, and you say, there are no IV drug
23 users in Pittsfield. But they are there. Where
24 they go for drugs is the major urban areas.

1 MR. GOLDMAN: But you could provide
2 care more targetedly if you could find the two
3 persons already infected with HIV and who are in
4 need of care.
5 MS. DOMB: But if you fund
6 treatment programs, they are able to provide
7 quality AIDS HIV education. Then you are
8 reaching those people and more in that setting.
9 MS. STRAWN: I was struck by Don's
10 question about why not housing. In New Haven we
11 are struggling with people for housing for IV
12 drug users with AIDS. The model we borrowed our
13 housing program from was the Los Angeles Shonte
14 housing model based for people, gay men, who
15 don't have the behavior that goes along with drug
16 use.
17 DR. ROBERTS: Shonte (phonetic)
18 explicitly excludes drug users.
19 MS. STRAWN: And most programs do.
20 It requires a level of staffing and licensing and
21 regulating that the Shonte program doesn't. It's
22 much more costly and takes much longer to put
23 into place.
24 DR. ROBERTS: So the point being

1 that the cost per case, as it were, of social
2 services is going to be very different for
3 different populations because some populations
4 are particularly difficult to serve.
5 MS. STRAWN: And particularly needy
6 and no care that's available now really knows
7 what to do with these folks, no system knows what
8 to do with these folks, active substance abusers
9 with HIV infection with all their needs.
10 DR. ROBERTS: I'm just struck by
11 the point we were talking about yesterday about
12 how to get people in. And in a sense, the
13 further out people are in terms of their
14 connectedness to the society, the harder it is to
15 get them in. As we do outreach, there's sort of
16 widening circles in terms of peoples' centrality
17 to the social system.
18 MS. STRAWN: If you could get
19 people into a housing program, that's such a
20 basic need and it gives you a captive audience,
21 then you can bring services in to them where they
22 live.
23 MR. BATCHELOR: I would like to
24 say, with part of me as the academic social

1 psychologist as well as public policy advocate
2 for people with HIV, the issue, the social issue
3 which covers IV drug users, gay men, women, on
4 and on, care providers, housing, drug use, and
5 it's been shown through research studies to make
6 a significant difference in peoples' lives and
7 peoples' health is the issue of social support.
8 It's also an issue where the federal government,
9 our 10 million points of light can make a
10 difference as well. This man here is from the
11 Boston Living Center which provides social
12 support and other activities for people with
13 HIV. Social support has been a major difference
14 in getting gay men to change their sexual
15 behavior.
16 DR. ROBERTS: Could you say more
17 about what you mean by social support in that
18 context because I don't think everybody
19 understands your reference.
20 MR. BATCHELOR: Social support is
21 either the reality or the perception that other
22 people believe what you believe. That is
23 perceived social support. If I want to go to bed
24 with you and you are my friend and you were my

1 friend and we've talked about it or I think that
2 you believe in safe sex, that's what you do, that
3 is just what you do. So that when you and I
4 negotiate going to bed, we don't negotiate safe
5 sex. It is perceived, there is the theory that
6 people talk about sex when they go to bed, but my
7 friends here say, well, this is what you do, then
8 that's what we will do, he and I. If he doesn't
9 want to do it, I'm much more likely to say, well,
10 I'm sorry, I don't want to have a sexual
11 relationship with you because my friends say this
12 is what we shall do.
13 In the same way, people who are on the
14 street shooting drugs, whether homeless or have
15 homes or if they work at IBM or they are on the
16 street, if other people in their system, their
17 social support system, their network, whether
18 it's close friends or just acquaintances, if they
19 say you clean your needle or you have a clean
20 one, if that's what they say and that's what the
21 belief system is, then that's what people tend to
22 do. That is something that the Feds can support
23 directly and/or indirectly by promoting systems
24 to get people together.

1 A recent study from Connecticut showed
2 that gay men who felt part of the gay community
3 and, therefore, had a source of social support
4 were much more likely to do safe sex, which is
5 difficult for the folks like Senator Helms who
6 don't want to recognize the gay community as a
7 community.
8 Similarly, programs that provide services
9 for IV drug users that allow them to get together
10 and relate to one another and don't say you're a
11 bad person but say respect yourself, respect
12 others, can support that kind of social support
13 network. And it's also the best way to get over
14 the psychological crisis of HIV positivity. It's
15 not psychotherapy. It's not drugs. It's
16 generally short-term social support groups so
17 that people get over their fear of being alone,
18 find out other people are in the same situation,
19 learn to cope as others cope, and then go on to
20 live their life and develop other social networks
21 that are supportive of positive change and
22 positive living.
23 MR. KESSLER: I just want to stay
24 back where we were for a brief moment in terms of

1 the $10 million, and I want to remind us to be
2 careful that when we talk about, it's been
3 interesting to hear people say IV drug abuse.
4 What we need to say is drug abuse because AIDS is
5 not just transmitted through IV needles.
6 In fact, the reason I inserted crack and
7 ice and cocaine is that they have other factors
8 associated with them in terms of economics,
9 prostitution, dealing, running, addiction to the
10 drug itself, which tends to encourage more
11 sexuality, sometimes sexuality, or usually
12 sexuality that is unsafe, sexual practices that
13 are unsafe, and so on.
14 And so when we, when Bennett or Bush talk
15 about drugs, they often talk about the needles.
16 And I'm also advocating at the same time for
17 clean needle exchange programs and changing the
18 laws that prohibit the sale of clean needles, but
19 we need to remember that people who do drugs are
20 also sexually active. And the new drug in the
21 gay community that everyone is using now is
22 Ecstacy, which is also leading to a lots of
23 unsafe sexual behavior. And the biggest drug
24 that's influencing more sexual misbehavior than

1 anything is alcohol, and that has to be
2 confronted. Not only in every community, but
3 when you, I would do the same thing with 10
4 million but I would phrase it slightly
5 differently, and that is put it into a variety of
6 treatment options that are marketed and
7 positioned for the various types of communities
8 that need treatment.
9 DR. ROBERTS: Could I push you
10 another step, Larry, because before when someone
11 made a sardonic comment about "just say no", do
12 we know, do you think there's anything about the
13 prevention of drug addiction as opposed to the
14 treatment of drug addiction? And what is it, I
15 mean prevention other than shooting down the
16 planes over the Caribbean. And what leads you to
17 think that it's more important to treat the
18 people who are already addicted than to, again
19 I'm not taking a position, I'm just asking you a
20 question, about why not go further down and say,
21 gee, I would spend it on preventing people from
22 being addicted.
23 MR. KESSLER: I believe if you put
24 all your money into the future cases, in terms of

1 prevention, you're going to write off all the
2 present users because they are going to die of
3 AIDS. They are going to get AIDS. The rate of
4 infection among users of various drugs is going
5 up significantly. So we need to do both.
6 But if I had a limited pool of money, I
7 guess I would go after those people who are
8 currently users and try to get them into
9 treatment. Then at some point down the pike when
10 they are fully in recovery, talk about testing
11 for HIV.
12 MS. DOMB: Are you talking about
13 drug use prevention?
14 DR. ROBERTS: Drug use prevention.
15 MS. DIAZ: I wanted to add
16 something to Walter's comment about creating the
17 social climate among the people that are users,
18 particularly so that something becomes
19 acceptable. I've been very fascinated with one
20 particular educational intervention, largely
21 funded by the CDC, and that is street outreach.
22 There are so many programs across the nation that
23 I visit and are doing street outreach in
24 different ways.

1 I understand that recently there was a
2 small meeting of people who were doing street
3 outreach which is not the same thing as getting
4 people into residential care. But there is a lot
5 of merit into that type of approach because it is
6 doing the very same type of thing Walter is
7 saying, at least for the users, of creating a
8 climate of this is what you should do if you're
9 going to use drugs.
10 I can tell you from some people that I've
11 actually seen doing the work in New York,
12 Phildadelphia, State of Washington, that the same
13 push to try to get support within the habit,
14 people that are using, is very essential because
15 at least that kind of parallel comparison that
16 you brought out is reaching people outside of us
17 not having full residential treatment facilities.
18 MR. BATCHELOR: Those same programs
19 are getting more people to decide to go into drug
20 treatment. It seems to be the most effective way
21 to get people to individually decide to go into
22 drug treatment.
23 MR. McEVOY: We opened in October.
24 We are seeing a lot of IV drug users coming in.

1 What's really quite interesting is most of these
2 people really want to separate and get out of the
3 drug culture. They are having a very difficult
4 time. We have got a support group. In fact,
5 after they come in after their urine tests and
6 say we've been clean for a week and are able to
7 give them that support, it's something they shoot
8 for.
9 DR. ROBERTS: You mean different
10 from the other shoot.
11 MR. McEVOY: In fact, you can see
12 the evidence of having that support and the fact
13 that these people now, although they are at best
14 intentions, they in fact want to move out of the
15 drug culture. In fact, some of them are in drug
16 treatment programs but they still need that
17 support which isn't there and they are flailing.
18 And in fact with the social support that they are
19 now getting in such an establishment, you can see
20 that it's direly needed in the fact that it
21 encourages them to get going.
22 DR. AMARO: You said what do we
23 know about prevention. There is a lot in the
24 scientific literature on prevention of drug

1 abuse. So this is not something we don't know
2 anything about. But, guess what, the answers
3 aren't simple, and they are expensive, and we
4 don't like to hear that.
5 The same thing for drug treatment. I
6 really think that sometimes, we've been framing
7 here do we do this or do we do that. Do we do
8 prevention or intervention, housing or drug
9 treatment. I really think we need to start
10 acknowledging the complexity of the solutions
11 that are involved here because we keep going for
12 the economically feasible within the current
13 framework and we end up getting in trouble.
14 An example of that is the turn to our
15 methadone treatment because people think it's
16 going to take care of it, it's going to bring
17 people into contact on a daily basis with
18 providers. I think it's a real mistake because
19 we know that people who are on methadone are
20 using other drugs for the most part. We know it
21 does not create the kind of changes in the social
22 network and the skills that an individual needs
23 to rehabilitate and to really become an active
24 and valued member of this society. But we keep

1 going for the cheap answer. And I think we
2 really need to stop falling into the pit of
3 framing questions, treatment or housing,
4 prevention or intervention.
5 The fact is that you have a continuum of
6 services that are needed. If you don't do
7 intervention, not only are those people going to
8 die, like Larry said, but chances are that they
9 in the process will infect other people. So this
10 is not a self-contained set of individuals.
11 So you are going to be doing yourself in
12 by trying to have such a myoptic view of the
13 issue that you end up really not addressing it.
14 MR. WHITE: I would like to echo
15 the comments made by Larry and by Walter. One is
16 I wish we would stop saying IV drug users and say
17 substance abusers or drug users. In
18 Philadadelphia the drug of choice is crack. We
19 are losing a whole generation of black females
20 because they are having 10 to 20 sex partners a
21 day for three to five dollars a sex partner. So
22 you can imagine what would happen if one person
23 who happened to be administrating or happened to
24 be doing some other things, infected ten people

1 in one day. And that could possibly happen.
2 Also, one of the things we are doing is a
3 lot of street outreach. We think that we are
4 successful when we go into a crack house or
5 shooting gallery, and the house lady has a bottle
6 of bleach there. Our outreach workers believe
7 they accomplished something because you don't use
8 if you don't clean your works. So there is some
9 benefit in the social aspects of this prospect of
10 trying to educate and get people involved.
11 We have noticed that with our peer
12 counseling with high school kids, they are
13 beginning to use condoms. And we're seeing
14 something other than just the prevention of
15 AIDS. We're seeing a decline in the pregnancy
16 among teenagers because of that.
17 The social grouping of people who we have
18 identified as being people who probably will be
19 high risk, the earlier we can get to them, the
20 better.
21 DR. FORSTEIN: I would like to
22 comment on what I hear is a problem in the way we
23 think about choice. You say what would you do
24 with $10 million. You know, if there were a

1 fireball that were coming from a galaxy headed
2 towards earth that we needed to fight off, we
3 wouldn't argue about should we build another
4 bridge or should we put $10 million towards the
5 fireball. It would be a clear sense that either
6 we destroy the fireball or we all die regardless
7 of how we decide to spend the $10 million.
8 There is a sense of the Hoover Dam is
9 cracking. There is one hole and we're putting
10 our finger in it, but the cracks are becoming so
11 great that the $10 million is not acceptable.
12 And when you start to think about taking $10
13 million for a problem in this country like
14 substance abuse and poverty, we feed into the
15 hopelessness that people really feel that there
16 is nothing you can do. If the question weren't
17 what would you do with $10 million but rather if
18 we think about what we need to do, how much money
19 would it take and how do we fund that over the
20 next decade.
21 We need a national army corps of health
22 educators, of drug prevention people. We need a
23 national corps of people, enough people to really
24 get into the communities. We need to look, and

1 this is what is being said, it's very expensive.
2 But if we think about the cost per case, you
3 think about how many cases, what would a
4 treatment be for someone with substance abuse,
5 what would a treatment be for women with
6 children, a gay men with X. Then you begin to
7 see what the tradeoffs are going to be in our
8 society, I really believe what paralyzes us is
9 it's astronomically high, and someone high up
10 knows that. Let's pick out something that for
11 tomorrow is going to feel like we're doing
12 something, even though we know that the rest of
13 the dam is cracking around us.
14 And how we as people talk about that
15 dichotomy between what we can do for the moment
16 and what we really need to do long term for the
17 dam that's cracking, how to put up a grid in
18 front of the whole dam to keep it in place long
19 enough to rebuild it is, I think, a very serious
20 dilemma.
21 DR. ROBERTS: Since metaphors,
22 obviously, are very important in this, do you
23 think that the fireball aimed at earth or the
24 cracking dam is the right metaphor? I just raise

1 that question because one of the things that I
2 perceive, we talked yesterday about the changes
3 in the epidemic. One of the things that I
4 perceive is that average heterosexual white
5 American no longer perceives themselves as living
6 below the dam; and that this has an impact on the
7 politics of the funding that you're raising. I
8 wonder if you could talk more about that.
9 DR. FORSTEIN: I think you're
10 absolutely right. I think it's the same issue
11 with poverty and homelessness, that for most
12 people it's not a fireball. The problem is we
13 can't rely on most people's perception of the
14 world to tell us what to do. We have to have
15 some leadership that says even though you
16 personally are not likely to get HIV infected,
17 the capacity for this society to continue to
18 provide for you the standard of living that you
19 want is going, you are an extinguishable species
20 because the rest of it is going to come crashing
21 down around you, and you are going to be the
22 aftershock. How we get people to perceive the
23 connectedness to each other is really the
24 problem.

1 DR. ROBERTS: Let's just push this
2 a second because the classic response is, first
3 of all, in a democracy what most people believe
4 does wind up mattering, either before or after
5 leadership, depending how the democracy is.
6 The second issue I want to push you on is
7 there is one thing to argue for leadership on the
8 grounds that if we don't deal with the dam you
9 will be hurt by the aftershock. And there's
10 another thing to argue for leadership on the
11 grounds that it's a moral obligation as members
12 of the common community.
13 I mean, the first is a sort of selfish
14 appeal and the second is a community solidarity-
15 based appeal. I just wonder, it's still not
16 clear to me which line or both.
17 DR. FORSTEIN: I think they are
18 inseparable.
19 MR. LEVI: And it's already
20 happening. It depends where you live, it's
21 already happening.
22 DR. ROBERTS: What's the it?
23 MR. LEVI: The system collapsing
24 around them. My aunt just died. She needed to

1 go to a hospital in a hurry. She had to wait
2 eleven hours to get a bed in a hospital, white,
3 elderly, middle class woman, absolutely no
4 connection with AIDS.
5 DR. ROBERTS: She lived in New
6 York?
7 MR. LEVI: New York. The
8 connection with AIDS was that one of the reasons
9 that hospital, one of, granted not the only, one
10 of the reasons that hospital couldn't find a bed
11 for her was because they were overwhelmed with
12 some of the burden associated with AIDS.
13 Now, the problem is that there is no
14 leadership in this country from the White House
15 or wherever making those connections that these
16 are indeed, that the impact, yes, you may think
17 you'll never get HIV but the systemic issues
18 associated with HIV are going to directly affect
19 your life when you least want them to affect your
20 life.
21 CHAIRMAN ALLEN: But you're also
22 looking at the backlash of anger. Be careful
23 there because what you're looking at, this is
24 affecting my life and we're going to push you

1 away. You are a throwaway person. You're acting
2 like people are going to respond lovingly to
3 that.
4 MR. LEVI: Ministers of our society
5 are supposed to teach people to be loving.
6 CHAIRMAN ALLEN: I know my
7 profession would enter this.
8 MS. ST. CYR: Our sense of
9 complacency is going to end up where Scott is
10 talking about right now because there is a
11 general sense of more homelessness around AIDS at
12 this point. What it will end up is we will have
13 that backlash regardless. But on these issues,
14 we are looking at survival factors all morning,
15 dealing with different populations at different
16 stages of their lives. The fact of the matter is
17 whether we want to be blunt or not about it. I
18 wish to be blunt.
19 We have not been morally responsible to
20 the population in terms of these factors of
21 survival, along the whole list that Larry brought
22 forth. It is sobering as we talk about
23 psychosocial factors that we still don't even
24 hear --

1 MS. AFFOUMADO: But we all think,
2 clearly what's happened, there's so many myths
3 that have abounded in the epidemic. One myth
4 which comes to mind right away when we talk about
5 abuses and substance abuse is that people who
6 have abusive behavior with chemical dependency
7 are not treatment compliant patients; they don't
8 care.
9 And we have found in New York City, for
10 example, in many of the programs which have
11 really been designed and put together to really
12 look at the needs of these populations, that they
13 have been better in terms of compliance than some
14 gay, middle class white men. There is a study at
15 Montefer that is a very good study to look at.
16 I think we also have to look at
17 disspelling a lot of the myths about population
18 in quite that we didn't want to take care of.
19 I think in terms of money and the
20 economy. If we, to use our capitalistic side
21 which I really am not comfortable with, but I can
22 sort of pull it out of my head a little bit at
23 this point, if we looked at this as a business,
24 we would have to invest a large sum of money in

1 our business so that at the end we would be able
2 to have a benefit. And we don't think of it in
3 those terms. What I hear around this table is
4 there is a whole idea of incremental planning and
5 reactive planning and crisis intervention. And
6 what I said yesterday about the value that we
7 don't place on prevention and sustaining the good
8 qualities of life, whatever those are in our
9 ethical and moral fiber, and so we don't invest
10 in those things. Somehow we are afraid to put a
11 dollar value on these very gray mythical kinds of
12 concepts.
13 We have double agendas in this country,
14 for example. All men are created equal.
15 Bullshit. We all know that that's just words.
16 All men are not created equal in this country.
17 This is not a democracy in the sense of that kind
18 of equality.
19 So we really have to look at what we're
20 talking about and what our value system is and
21 where it takes us in terms of understanding what
22 the needs are and how many of the myths have got
23 to be dispelled before we really can go on and
24 really look at what has to be done; and that

1 these things are really complete systems, not
2 just hit and miss quick fixes. We can't just
3 give people AZT when they are still doing drugs.
4 That is unethical in my point of view. We don't
5 know what we're doing to them, so we have to talk
6 about treatment.
7 I could go on, but I don't want to. But I
8 think the message is that we have to rebuild.
9 DR. ROBERTS: I want to push you.
10 I want to play devil's advocate for a minute
11 because obviously the practical problem is is the
12 great the enemy of the good. It's one thing to
13 say, gee, we need complete systems, it's very
14 complicated, we need housing, we need drug
15 treatment, we need this population and that
16 population, and the democracy isn't perfect, and
17 if we had leadership from the White House. But
18 given what Scott said and what Marie said, a
19 cynic would say the politics are such that you
20 are likely not to get all the money you would
21 like to have for your ideal system. And the
22 question I guess I'm trying to ask you is how do
23 you respond to that?
24 MS. AFFOUMADO: I think maybe what

1 we have to do is play the game. Maybe the game
2 is that we start talking the business entity kind
3 of idea. If that's what comfortable in terms of
4 the people that are holding this money and making
5 decisions about how it gets spent, and I'm not
6 comfortable with that, but maybe we have to look
7 at it.
8 DR. ROBERTS: I don't understand
9 what you mean.
10 MS. AFFOUMADO: Maybe Jeff's
11 example of his grandmother, I've heard this story
12 a million times already about emergency rooms and
13 people not getting care.
14 DR. ROBERTS: There aren't enough
15 votes in the Congress out of New York City.
16 MS. AFFOUMADO: I know what you're
17 saying, that maybe that comes out of the
18 backlash.
19 MR. LEVI: But you're turning the
20 question around in a way. It's a way of putting
21 it. Since you're not going to get everything
22 except whatever it is that we're going to give
23 you. Particularly, in the business of meeting to
24 the National Commission on AIDS, which we are, I

1 think it's important to point out that if we
2 don't start looking at it systematically, if we
3 say we can only deal with the homeless system and
4 not the rest, you're guaranteeing failure because
5 the entire problem of AIDS or drug abuse or
6 whatever it may be will not be solved by
7 addressing one piece of the puzzle.
8 If you don't take a systematic approach
9 and if this Commission doesn't advise the nation
10 to take a systematic approach, then by putting
11 all that pressure on one piece of it, that will
12 fail, and George Bush will say, hey, we gave you
13 what you asked for and it failed.
14 DR. ROBERTS: Let me push Mindy's
15 area a further step, when you say if we don't
16 take a systemic approach. The question is what
17 is the system? Is it the AIDS system? Is it HIV
18 plus drug abuse, is that the systemic approach?
19 Is it HIV plus drug abuse plus poverty and
20 homelessness?
21 When you say we need a systemic approach,
22 I just want to know how broadly you're drawing
23 the boundary.
24 MR. LEVI: When this Commission is

1 looking at it, it has to be how HIV fits into
2 each of them: How HIV relates to homelessness,
3 how it relates to health care financing, how it
4 relates to drug abuse. And perhaps year by year
5 you whittle away at each of those aspects and
6 you're not going to get them all legislated or
7 changed in one year, but you do it with a broader
8 vision in mind. And when you do something about
9 HIV and homelessness, you don't say the problem
10 is solved but this is all we can do, but you say
11 this is the first of many steps that we are going
12 to take.
13 MS. DOMB: I was going to say that
14 it's not only how does HIV fit into each of
15 those, but it also is historically, since the
16 epidemic was first recognized, AIDS has kind of
17 illustrated the failures in the whole system. So
18 you can go beyond that.
19 It's the conflict that I think we all face
20 when we're involved with AIDS or HIV is which one
21 do we take on. You put it beautifully,
22 Marshall. We all know that AIDS is sort of the
23 epitome for every failure that we've turned away
24 from in the past two or three decades, but at the

1 same time it's its only crisis. How do you deal
2 with the systematic crisis that allows for an HIV
3 epidemic to get out of control, to some degree,
4 and then at the same time how do you deal with
5 the system? I think we have to do both.
6 I think that Jeff's point is well taken,
7 that you kind of have to sit back and say swallow
8 your gut, and say I can't take on the whole thing
9 and I've got to get a shelter because they have
10 no other place to go. And being on the street
11 that night is going to be worse than not being
12 with a roof over their heads. But at the same
13 time they are not the only ones entitled to a
14 shelter. There are people who are dying from
15 frostbite who aren't HIV infected.
16 So we build coalitions. And one of the
17 coalitions was for the disability act, where many
18 people of different communities join together to
19 get a disability rights law on the books, people
20 who are involved with other kinds of physical
21 disabilities, so we extend our reach
22 systematically.
23 MR. KESSLER: One of the words that
24 was used, it's almost becoming a buzz word

1 because it comes up at every Commission hearing,
2 and that's the whole issue of leadership. But I
3 want to add to that buzz word the whole concept
4 of advocacy.
5 What part of the problem is, when we talk
6 about increasing the pie or enlarging the funds
7 that will deal with all these social issues,
8 legislators, governors, mayors say you've got to
9 go back to educate my constituents. You've got
10 to educate the population of Massachusetts, the
11 City of Boston, so that they will support this
12 tax increase that you're advocating. I think
13 that's ass backwards. I mean, they are elected
14 to help educate the public about the needs, the
15 social needs, the health needs, whatever.
16 It's not my -- I can't do both, run an
17 agency, and the people who work for me can't also
18 care for people, and at the same time be at the
19 State House eight hours a day, educating them but
20 then having them come back and say you have to
21 throw a protest up here to make it look like
22 we're really screwing you so that we can get the
23 angst level up if the Globe covers it. And all
24 of that is such a twist on how we build a climate

1 of compassion.

2 MS. DOMB: I don't want to seem

3 like I'm disagreeing with a Commission member,

4 necessarily, particularly since we're from the

5 same state, but I'm not so sure if that's ass

6 backwards. The health education programs that

7 are in many countries, it's proven that when they

8 come from the top down they don't work, and when

9 they come from the bottom up, they do work. And

10 from the bottom up, I think it's sort of sad that

11 we look at people from the bottom, but as an AIDS

12 educator pretty much out in the boonies, I have

13 to educate people in politics otherwise I'm not

14 doing my job. I have to educate people on the

15 history of the epidemic so they will understand

16 the context of AIDS, that we're not really

17 learning about how HIV relates to the T-cell.

18 We're learning about how long it took the

19 government to fund anything.

20 I think that does become an AIDS educato's

21 job to do that. It's just as much as to be

22 forced upon touching on homophobia in discussion

23 groups, and other issues that aren't technically

24 AIDS related, but in the context that AIDS

LEADERSHIP

1 happens.

2 MR. KESSLER: What I'm trying to

3 say is they want us to educate about AIDS, but

4 they also want us to educate about why taxes

5 should be raised. So we're now doing two

6 things. We're educating people about taxes and

7 educating them about human suffering.

8 DR. ROBERTS: But let me again push

9 you from the devil's advocate point of view. If

10 people who believe, presumably if we had Governor

11 Dukakis in the room, he would say to you if

12 people who believe strongly about the

13 desirability of expanded services don't go out

14 and make the case for expanded taxes, I can't get

15 it through the legislature, and I've lost, George

16 Keverian and I have now lost this four times.

17 And if George Bush is successful with no new

18 taxes, read my lips, then that has an impact on

19 the amount. Why is it not the responsibility of

20 the advocacy community to urge tax increases?

21 MR. KESSLER: I think it's a dual

22 responsibility. When we talk about leadership,

23 when George Bush did his August talk on drugs, he

24 didn't do what Rona advocated, and that is use

1 some flow charts that showed the connection
2 between this war on drugs, the eighth annual war
3 on drugs, and the connection between that and
4 AIDS and the investment in the future. He talks
5 about investment in our children because that's a
6 neat phrase, but the investment really is much
7 broader than whether the five-year olds --
8 DR. ROBERTS: The question isn't
9 he's not doing his job --
10 MR. KESSLER: It's a leadership
11 issue. Helping people see the connections.
12 DR. ROBERTS: But what's your part
13 of the job?
14 MR. KESSLER: Our part is to
15 deliver some of the services, if we were
16 adequately funded, and to help build the climate
17 from the bottom up. It has to be built from both
18 directions so that there is a climate of
19 compassion, that there are adequate services,
20 that the social fabric and the safety net meet.
21 DR. ROBERTS: So you don't disagree
22 with Minday saying that people in the delivery
23 arena do have a responsibility to advocate for
24 expanded funding and for higher taxes?

1 MR. KESSLER: No. But I don't want
2 that to become the full-time job of my agency or
3 the Dimmock Health Center or any other place that
4 has another mission. We are, in the last two
5 years we have been called in so many times and
6 told the only way we can get this amount of money
7 is if you guys go out and raise some hell, if you
8 hit the streets or do a sit-in or do something
9 else. And yet that now is beginning to fail now,
10 too, because there's a certain skepticism about
11 those activities.
12 MR. LEVI: There is also a
13 fundamental conflict that you're imposing on
14 groups like Larry's which get state and federal
15 money. And at the same time those same state and
16 federal officials are saying go lobby and go
17 advocate, and if they do too much lobbying and
18 advocating they'll lose their 5013(C) status and
19 eligibility for federal funds.
20 Clearly there is a responsibility for that
21 kind of advocacy, and I assume you know how much
22 advocacy has come out of the AIDS and gay
23 communities around these issues both out of the
24 local and national level. But that is not solely

1 the responsibility. I mean, it is as much the
2 responsibility of academics at Harvard University
3 who see what's going on and probably have more
4 access than the rest of us do to decision-makers
5 to sit down with investors and congressman and
6 say this is screwed up and you should be doing it
7 and it doesn't matter whether it's the bottom
8 percent of the population or the top, you need to
9 be doing it because I sitting in my ivory tower
10 see the systemic issues.
11 DR. ROBERTS: Let's just be clear.
12 I am playing devil's advocate, Jeff, and taking
13 that position seriously --
14 MR. GOLDMAN: I would like to ask
15 Jeff or anybody else, are you suggesting that the
16 Commission would deal with the whole systemic
17 problem, is there an implication or suggestion
18 that the topic that this meeting is called for
19 here today, namely HIV testing, is too segmented
20 and too small a portion for the Commission to
21 deal with as a matter of your recommendation, to
22 deal with at all without having, outside of the
23 context of those larger issues, which might be a
24 more significant job to deal with?

1 MS. DOMB: Can you repeat that?
2 MR. GOLDMAN: Is it appropriate to
3 deal with such a small segment of the whole
4 global issues that clearly are so important to
5 deal with in terms of HIV testing? And is it
6 something that perhaps the Commission ought to
7 defer dealing with until it first deals with all
8 of those other issues? And it may be the answer
9 to the question that what recommendations ought
10 the Commission come out with in terms of HIV
11 testing, or the Commission ought not deal with
12 the issue of HIV testing until it first deals
13 with the issues of poverty and jobs and social
14 services.
15 And is it too fragmented an issue outside
16 of that whole larger --
17 MR. BATCHELOR: You're trying to
18 make AIDS the cure, and AIDS is the disease.
19 AIDS may point out some of these problems but
20 also points out a lot of the strength in the
21 system, and in human nature and democratic
22 process and on and on. And yet, community health
23 centers and agencies dealing with strange
24 diseases and unusual diseases have always had to

1 advocate and do sit-ins.

2 MR. GOLDMAN: But HIV testing, not

3 AIDS --

4 MR. BATCHELOR: Genetic testing

5 before AIDS testing was bringing up very similar

6 problems. Problems have always been there. AIDS

7 has pointed some of them out. But if we wait to

8 cure all of the other problems before we deal

9 with addressing some idea of cure or whatever,

10 prevention of AIDS, then this is the President's

11 Commission on the World's problems. This is the

12 President's Commission on AIDS, and you can focus

13 --

14 DR. HINMAN: The National

15 Commission, not the President's Commission.

16 MR. BATCHELOR: But to address the

17 issue of AIDS and what we can do about solving it

18 is something this Commission can do because we

19 have been talking problems for many hours. I

20 think we need to talk about some solutions.

21 DR. ROBERTS: Marshall and then

22 Larry and then we break for lunch. When we come

23 back we are going to take Walter's injunction

24 seriously about talking about positive

1 recommendations.

2 DR. FORSTEIN: I would like to

3 suggest that they are not necessarily mutually

4 exclusive to do both at the same time. In fact,

5 if the Commission can serve no more purpose than

6 to get people in leadership positions to see the

7 complexity of the problems and to then figure out

8 a strategic way to begin to approach some of

9 those problems that are doable in the short term

10 but which don't by doing in the short term

11 undermine the long term, if we can get the

12 Commission in a sense to take HIV testing as a

13 paradramatic problem that can be both addressed

14 in and of itself but also points out the

15 connectedness with other social issues which have

16 to be addressed in order for HIV testing to have

17 any benefit in the whole spectrum of disease.

18 The Commission can teach people how to think as

19 much as they can teach people how to do.

20 That is a major problem that I see is the

21 way in which we dichotomize and simplify as

22 opposed to expand and connect. We only have so

23 much money in one particular area to start with

24 and we need to argue where to do that. But if

1 you're taking $10 million, if that's all you've
2 got, and you're putting it X but you realize if
3 you put it in X this way, it doesn't five years
4 from now undermine, but if you put it in Y it may
5 help, that's a very different way of thinking
6 about the short-term connectedness to the long
7 term.
8 MR. KESSLER: I think Marshall said
9 most of what I was going to say, and that is the
10 people around this table have seen the
11 interconnectedness element in this meeting, and
12 we've just been able to articulate it better. I
13 think that's kind of helpful to keep finding the
14 new words to describe our frustration as well as
15 our vision.
16 But in terms of Walter's remarks, too, I
17 think one of the things we could easily do,
18 almost, is simply take the report and insert AIDS
19 because it's the same sort of conditions are
20 still there except that the new problem that's
21 ripping the society apart, an additional problem
22 to racism, poverty, is AIDS. But there, too, the
23 intersection is real clear.
24 So we haven't learned much from the mid

1 and late Sixties about how communities fall apart
2 and respond and react, and now we have this other
3 thing, this new drop of oil on this scalding
4 caldron here, and it's AIDS. And the other big
5 drop is addiction. And the two of them, you
6 know, are intersecting, and the metaphor on the
7 dam or the earthquake metaphor is the gridlock
8 metaphor that I often use, and that is that these
9 two epidemics are leading the gridlock. What
10 happens when you have gridlock is it doesn't
11 matter whether you have a driver's license or
12 not; you can't move. We are approaching the
13 point where you can't move.
14 We don't have many options but to sit
15 there and become frustrated, more hopeless,
16 despondent and more hopeless, and the car is
17 running out of gas.
18 DR. ROBERTS: All right. We will
19 reconvene in exactly one hour. There is not much
20 time for the aftersoon session so let's try to
21 actually make it an hour, if we could.
22 (Recessed for lunch at
23 12:30 p.m.)
24

1

2 AFTERNOON SESSION

3 (Resumed at 1:35 p.m.)

4 DR. ROBERTS: Walter isn't here. I

5 was going to let him lead off since he told us

6 that we ought to begin with the question of

7 solutions as opposed to problems. But I wondered

8 if any of you would like to lead us off and say

9 from your perspective what the real priorities

10 are about the directions in which the Commission

11 ought to go. Important points of industries and

12 emphasis in terms of psychosocial services,

13 places where you think the system is really

14 failing.

15 MS. STRAWN: One of the things that

16 we talked a lot about was access to services and

17 pointed up the problems with that. But one of

18 the things we didn't talk about, and I'd be

19 interested in Marshall's response, but anyway,

20 I'm not sure the mental health folks are ready to

21 deal with AIDS. In fact, the psychiatric/

22 psychological profession has been really

23 reluctant to embrace AIDS, more reluctant than

24 the medical profession.

1 DR. ROBERTS: Even more reluctant.
2 MS. STRAWN: So there's beefing up
3 services, but then important training needs that
4 we did mention this morning, particularly for
5 mental health folks.
6 MR. GOLDMAN: I want to ask a
7 question along those lines. There has always
8 been an almost, in a lot of different arenas,
9 conflicts in terms of allocation of resources
10 between outreach on one hand, provision of access
11 to services on the other hand, and then what I
12 would call training problems on the other hand.
13 In other words, what's the point of doing
14 outreach if there isn't access to facilities, and
15 what's the point of access to facilities, if
16 there aren't people to do it. Therefore,
17 logically speaking, what you ought to spend your
18 first dollars on is training people so there's
19 access when you do your outreach. And one could
20 argue that's the way to do it.
21 I think what ends up happening is that
22 there is a balance between those and that at
23 various points along the line and at various
24 times and perhaps in various localities there are

1 different kinds of bottlenecks that at one point
2 in time the bottleneck might be the lack of
3 facilities. And at another point there are
4 plenty of facilities but no professionals there
5 to operate the facilities, and at other times
6 there may be plenty of facilities but you need
7 outreach programs to bring more people into it.
8 One question that I would have is are BALANCE
9 there any generalizations that one can make, OUTREACH
10 should each locality make its own determination TREATMENT
11 with respect to how to balance between those? Is
12 there something that ought to be done at a
13 national level to deal with that? Or is it more
14 simply a local issue, or is there one place along
15 that continuum that the Commission wants to make
16 recommendations on for both?
17 MS. DIAZ: I'm sorry Joe isn't here
18 because I thought that was the very essence of
19 the HRSA AIDS service demonstration projects,
20 Don. All the work is not in on the first set of
21 projects, which were four, as he described
22 yesterday, but with 25 additional pilots around
23 the country we ought to have a pretty good idea
24 within the next year of that triad of facilities

1 and resources and personnel and needs of the
2 population to get them to those services.
3 So I really think that a lot is resting on
4 that particular issue.
5 DR. ROBERTS: What I heard Don
6 saying was where do we perceive the real limits
7 are in terms of providing additional services,
8 and are those limits the same in different parts
9 of the country or different in different parts of
10 the country.
11 MS. DIAZ: That's what those
12 demonstration projects are, the four initial
13 ones. The report is almost in. We're talking
14 Miami, New York, Los Angeles and San Francisco.
15 That is just about in. The HRSA Advisory, AIDS
16 Advisory Committee is going to be reviewing this
17 because that material is coming in from those
18 first four.
19 But in addition to that, there's 25 pilot
20 areas studying the very thing, providing the
21 answer to his question.
22 CHAIRMAN ALLEN: Are you sure HRSA
23 has an evaluation mechanism?
24 MS. DIAZ: To those, yes.

1 CHAIRMAN ALLEN: Have you seen it?

2 MS. DIAZ: Yes, for a couple of

3 areas. And I understand that that's how they

4 funded the others with an evaluation component.

5 But a heavy common thread to all of those is an

6 establishment of a community-based case

7 management system that looks after not letting

8 people fall between the cracks.

9 DR. ROBERTS: Other views and

10 following Walter's proposed program about what it

11 is we need to do? We could end this meeting

12 early and let the Commission meet, and we could

13 all go fight the ice and snow.

14 MR. LEVI: Well, we really haven't

15 grappled with the care financing part of this.

16 Even if we come up with a model, we still have to

17 figure out a way to pay for it. I think one of

18 the issues that the Commission certainly has to

19 face, and it comes back to the whole question as

20 to whether we create something around HIV or we

21 deal with some of the systemic issues, is do we

22 resolve those access to this perfect system that

23 we have now created through traditional financing

24 mechanisms or something that is unique to HIV?

1 And my bias would be that if we are trying
2 to create the precedent of a commitment to
3 providing for this range of services and
4 treatment and whatever it may be for anyone with
5 a serious illness like HIV, then we need to be
6 trying, even putting aside the issue of whether
7 you have an AIDS specific or HIV specific site,
8 you try to integrate at least the financing into
9 the existing system.
10 To me, that would imply, for example, and
11 I'm going to get myself in a lot of trouble
12 saying this on the record, but I'm going to say
13 it anyway, an example of how we've done it wrong
14 and how we could do it right, that came up
15 earlier. When the funding for AZT is, and I
16 plead guilty because I supported it and it was
17 right to do it and it's right to continue it, but
18 had we to do it all over again, I think I would
19 do it differently if we could. The special
20 program for AZT and related drugs now is not
21 logical. The logical thing to have done is to
22 create some sort of system within the Medicaid
23 program so people would, so that it is truly
24 integrated into the system that we have in this

1 country for dealing with poverty issues
2 associated with medical care. And that's what I
3 think.
4 I know people in Congress are looking at
5 it, and I hope this Commission will look at it as
6 well, is the notion of creating special access,
7 creating access to HIV-related care through the
8 Medicaid system.
9 CHAIRMAN ALLEN: I have a question
10 about the financing. Do you feel that the
11 proportion of financing in regards to testing and
12 early intervention, if that is the correct
13 proportion? We could ask for more money, but we
14 can also say this is a correct way to spend what
15 we've got. I want to know your opinion.
16 MR. DALTON: There is a separate
17 working group here that is dealing with bigger
18 health care financing. I think what Scott is
19 trying to do is to figure out how we can feed
20 into the kinds of concerns we've been talking
21 about for the last couple of days. If there are
22 distortions in the proportions in the way money
23 is being spent from the perspective of the people
24 in this room, that's certainly something we've

1 got to do. But this is not the place to take --

2 MR. LEVI: But the beauty of

3 putting care in Medicaid, that doesn't come out

4 of the 1.6 billion dollars.

5 MS. GELFAND: It just seems to me

6 that the bulk of the money is going into testing

7 and it's not linked to the concept of early

8 intervention; and that totally simplistic way, I

9 think that we have to stop testing until we can

10 guarantee everybody walking through that site

11 testing positive, who wants it, a medical

12 evaluation. We can't do that. We can't do that

13 in Los Angeles, for sure. And until we can do

14 that, I think --

15 DR. ROBERTS: What do you mean by a

16 medical evaluation?

17 MS. GELFAND: Base line medical

18 evaluation including T-cells. As basic as that.

19 And a physical exam.

20 MR. BATCHELOR: A follow-up to save

21 money in the long run would be just to do T-cell

22 testing.

23 MS. GELFAND: It really scares me

24 when I hear yesterday this America Responds To

1 AIDS is get tested. I'm willing to close the
2 doors of a test site unless they're going to give
3 us more funds because it's not fair. It's not
4 fair.
5 DR. ROBERTS: What's unethical,
6 Rona?
7 MS. AFFOUMADO: I think again to go
8 back to some of the comments that I've made and
9 other people have made, we can't do treatment
10 specific. We can't do service specific. We are
11 looking at continuums, looking at coordinated
12 services to tell somebody that they are HIV
13 positive and, yes, they have 200 T-cells and send
14 them away is worse than being done to begin
15 with.
16 I think, again, to go one step further and
17 say you're HIV positive, you have 200 T-cells and
18 we're going to do a physical exam on you and then
19 send them away again is still inappropriate. I
20 think we've got to get through the notion of this
21 longer-term comprehensive care model that
22 includes medical, psychosocial, concrete social
23 services and all of that. And, again, to get
24 back -- which is a big problem, but we have to,

1 if we keep talking about little pieces of this
2 pie, then that's what we're going to keep going
3 after. And if we keep saying, well, it's this as
4 opposed to this, then that's what we're going to
5 keep going after.
6 All of us who are working in this and all
7 of us who are trying to learn and understand this
8 have to keep saying comprehensive, total
9 packages. I know it's almost Pollyanna because
10 of the funding issues, but if we don't, then what
11 we're going to do is what we've done in the
12 past. We all have to take responsibility for
13 what we have done in the past because we have in
14 some ways, all of us who have worked in these
15 kinds of issues before, have created the kind of
16 system we have now.
17 MS. GELFAND: But in the meantime,
18 this has already started.
19 MS. AFFOUMADO: I think it's our
20 job to say stop. Before you do this --
21 DR. ROBERTS: Do you agree with
22 Jackie? You ought to close the doors of the test
23 sites until you have comprehensive medical and
24 social services for everybody that tests

1 positive?

2 MS. DOMB: No. That's what we had

3 in western Massachusetts. The only people doing

4 AIDS work were federally funded ATS counselors,

5 who then got involved in trying to create

6 services. It was sort of a bandaid approach, but

7 it at least got things moving.

8 MR. BATCHELOR: There certainly are

9 an awful lot of people who don't have health

10 insurance or don't have eligibility for Medicare

11 or Medicaid or for various reasons cannot find

12 care, but yet this is not the worst system in the

13 whole world we have in the United States. The

14 vast majority of people do have health

15 insurance. People do have access to a network of

16 community health services. Community health

17 centers don't generally provide services for HIV

18 because their focus is on chronic and mentally

19 ill. But the vast majority of people can get

20 care. That doesn't diminish the needs of people

21 who can't.

22 DR. ROBERTS: The vast majority of

23 people can get care. Now we have a real

24 disagreement on the table.

1 MS. ST. CYR: I don't think you're
2 talking about vast majority. What concentration
3 of majorities are you talking about? In all
4 seriousness, the vast majority of people in my
5 community can't get care. It took us a year to
6 get medical coverage as workers. We couldn't
7 even get medical coverage from an insurance
8 company for lack of ability to pay. And when we
9 were able to pay, just because our names were in
10 an AIDS resource it was difficult.
11 So when you're talking, you need to put it
12 in perspective. Even when you are considering
13 the strategies and solutions, you need to put in
14 perspective what people, what majorities, what
15 groups that you are talking about. And I don't
16 think we do that very well.
17 MR. DALTON: At least eight or nine
18 people came in after I did. Just so people know
19 what we're talking about, can you go back?
20 DR. ROBERTS: I propose that we, as
21 I said, that we start with the agenda Walter put
22 to us on the question of positive suggestions of
23 what we ought to do. And we, Jeff said that we
24 have to deal with the issue of financing and that

1 if he had it to do all over again, he would have
2 thought harder about finding a way to finance AZT
3 that was integrated with the rest of the health
4 care financing system. And I think that is
5 really sort of what provoked the current
6 conversation.
7 The question I want to put back to Jeff,
8 and it's one that you and I discussed briefly
9 yesterday, and maybe you can push further, what
10 do you think about going back to what people said
11 this morning about the need to solve the system
12 problems, including points that you, yourself,
13 made, what do you think about categorical versus
14 general funding?
15 MR. LEVI: Well, define your terms
16 better in terms of categorical and general
17 funding. Are you talking about the $10 million?
18 DR. ROBERTS: No. In general, we
19 had a brief discussion yesterday about the
20 relevance of the ESRD model or whatever, and you
21 mentioned again the question of whether AIDS
22 should be distinctly funded and, therefore,
23 whether people with some diseases should have
24 access to services that other people in

1 comparable circumstances but with different
2 diseases.
3 We have the situation now that if your
4 kidney fails you are covered, and if your
5 pancreas fails, you're not, which is arguably a
6 little bizarre.
7 MR. LEVI: Unfortunately, end stage
8 renal disease is sort of this strong arm of not
9 the way to do things. I guess it depends on what
10 part of the HIV problem we're talking about, as
11 to whether I would talk about categorical or
12 discretionary funds.
13 I think in the context of care financing,
14 particularly, I would look towards categorical
15 funds for both systemic reasons and very
16 practical political reasons. The systemic
17 reasons are the degree to which care financing is
18 a problem for HIV as related to peoples' level of
19 income, and it's a larger part of the poverty
20 issue, and, therefore, we should solve it within
21 a poverty structure; and that is Medicaid.
22 There is a second reason for doing it that
23 way because all you need is one vote to vote it
24 in. And if you do it through a discretionary

1 program, you have to refund it every single
2 year. And once people discover how much it's
3 going to cost over the long term, they may become
4 increasingly reluctant to fund it.
5 So when you do it through the Medicaid
6 program, I think the right will be there
7 indefinitely unless Congress votes to remove it.
8 The second -- but there are parts of the
9 HIV problem that belong as discretionary programs
10 because they are so AIDS specific and because
11 that is also the way the system deals with
12 disease prevention and control efforts. Whether
13 it's some of the testing, whether it's the
14 prevention and education program, whether it's
15 the model demonstration care programs, whether
16 it's some of the support for the community health
17 centers that are providing a lot of the care for
18 poor people, those happen through discretionary
19 programs. So it's going to be a mix. It's going
20 to be a mix of discretionary and categorical
21 programs. It's going to be a mix of HIV specific
22 and general ones.
23 DR. ROBERTS: If we could, just so
24 that we get the issue clearly on the table, the

1 argument over ESRD is in part an argument over
2 whether or not you ought to be eligible for
3 Medicaid if you have a certain medical
4 condition --
5 MR. LEVI: Medicare.
6 DR. ROBERTS: Regardless of income
7 tests that would ordinarily apply. So the
8 question to you is, is that a model one should
9 look for to HIV; that is, HIV also ought to be
10 exempt from the income tests which ordinarily
11 apply as ESRD is, or is it just a question of
12 strengthening Medicare generally?
13 When you talk about using categorical
14 money, it wasn't clear to me what you were
15 saying.
16 MR. DALTON: Before you answer, my
17 concern is that we have very little time with
18 this group together. There is another working
19 group which is going to be working for the better
20 part of two years on these subjects. We can tell
21 them what information we got in an hour, half an
22 hour, on a nice Friday in Boston, but my sense is
23 they are not going to be moved by what we have to
24 say.

1 So insofar as this is connected to the
2 issues we have been discussing for the last two
3 days --
4 DR. ROBERTS: Fine. Let's move on.
5 MR. WHITE: What's ESRD?
6 DR. ROBERTS: End stage renal
7 disease.
8 CHAIRMAN ALLEN: My original
9 question was are we correctly distributing
10 funds? Should we focus on the redistribution of
11 funds? I suggest that as a Commission in light
12 of the fact that there is not sufficient early
13 intervention, either support it with more money
14 or let's look at the way we are dealing with this
15 issue because here we are. We are about to walk
16 into early intervention. What do you think the
17 Commission should say? This is what this whole
18 thing is about, testing and early intervention.
19 I'm not saying that we should avoid
20 testing. There are other reasons to test. But
21 we should not advertise those as testing for
22 early intervention if it's not there. So is this
23 really helping?
24 As Marshall said earlier, does the test

1 really help or does it drive people to despair?
2 And, actually, convolute the whole issues. I
3 would like to get back to that.
4 MR. DALTON: I don't want to narrow
5 it to that. It seems there are any number of
6 issues that people may have that are connected.
7 DR. NOVICK: I want to address that
8 in a sense. I see the number one issue in the
9 global sense is health care planning for each of
10 the different communities. It's become obvious
11 to us that we represent very different
12 communities. All of our patients are indigent;
13 all of them, or almost all, are involved in
14 substance abuse. And our city as a result of
15 having such a large indigent and substance
16 abusing population is very poor, so it has few
17 resources and so on. Each of us has a community
18 that has those special features. So for me, drug
19 abuse issues are very important.
20 But, anyway, what I'm saying is that I
21 think the top priority is locality health care
22 planning because this kind of health care, early
23 intervention is delivered in a locality with its
24 own special problems. And most of our cities and

1 most of our counties and most of our states have
2 not opened that door. That is, I would say there
3 may be twenty cities in the country that have
4 opened the door.
5 DR. ROBERTS: So your answer to
6 Scott in part is the priorities will vary from
7 community to community so it's hard to make a
8 generalization.
9 CHAIRMAN ALLEN: I have a question
10 for HRSA at that point. Hasn't the budget been
11 eliminated for health care planning?
12 DR. O'NEILL: The health care
13 planning program, there was no request in the '91
14 budget.
15 MS. AFFOUMADO: A point of
16 information on the health planning. Many of the
17 HSAs across the country have been dismantled.
18 There are very few of them that have full staff
19 in operation. There has been no new funding for
20 health planning activities. I would say that's
21 in the last four or five years.
22 In New York state recently the AIDS
23 Institute gave the local clinic $150,000 to put
24 together a coordinated health plan for New York

1 City and the greater metropolitan area, but in
2 some ways it's a very bad attempt and a very
3 minimal attempt at trying to do a real health
4 plan. So it's a real issue.
5 MS. DOMB: I have a couple of
6 things I would like to put on the table before
7 the Commission. I appreciate being called. I am
8 unfortunately going to have to leave early
9 today.
10 Though it sounded like I was disagreeing
11 with what Jackie was saying, I share her concern
12 that by talking about early intervention and
13 testing before we have the network in place, the
14 most minimal way of saying is we're putting the
15 cart before the horse, but it carries much more
16 serious ramifications. So I would personally
17 urge the Commission to oppose any efforts to
18 promote early intervention or to link early
19 intervention and testing without also giving some
20 equal time to the need for resources into
21 developing a health care system that can receive,
22 and a whole network for training needs and other
23 kinds of reimbursement needs that can accept the
24 whole pool of people that are going to be turned

1 down.

2 I, also, and I'm just going to put these

3 out and maybe they'll serve as discussion, I

4 think the Commission should oppose any effort on

5 the part of the Centers For Disease Control and

6 Public Health Service to promote testing without

7 counseling. I think that is going to do the most

8 harm to any AIDS education effort going on

9 anywhere in the country because it's going to

10 promote the idea that testing is prevention when

11 it's not. It's going to make AIDS education

12 experts' jobs harder because it's going to

13 circumvent any effort of counseling we put in.

14 Where people who have maybe shared a drink with

15 somebody are going to be flooding alternative

16 test sites saying I thought I could get AIDS.

17 In response to that, Walter had said

18 earlier that education is really the entry into

19 the system. For many places in the country,

20 testing is the first time they are getting

21 education because they are getting counseling. I

22 think we have to realize that we can be AIDS

23 educators but counselors can also be AIDS

24 educators on a one-on-one basis. I think

1 anything the Commission can do to support the
2 morale of the counselors will be helpful.
3 I think that you should urge all
4 physicians to do counseling before testing. I
5 know from New York and Los Angeles, it seems like
6 a very basic thing. Well, of course, every
7 physician is counseling a patient. That's not
8 true. Many doctors don't know anything about the
9 test. We have to counsel them.
10 I also think in line with the issue of not
11 supporting any program that emphasizes testing at
12 the expense of counseling that we should lend a
13 little hand to support Bob's group in
14 Phildadelphia and oppose any efforts to promote
15 quotas for blood samples and not quotas for
16 counseling hours. I think epidimiological
17 surveys are important to finding out the scope of
18 the epidemic. I can give you the whole paragraph
19 description of the program, but I think that's
20 horrendous that we should tie or link that a
21 counseling program's funding is going to be
22 restricted if they don't get enough blood on the
23 table. That's not the point of a counseling
24 program. That's the point of the family

1 surveys. There should be a difference.

2 If the family surveys are for the public,

3 that's what they are for. Counseling programs

4 are for the individual.

5 MR. GOLDMAN: Are you willing to

6 forego the funding from the sources that require

7 the kind of epidimiological survey as the handle

8 to justify their funding --

9 MS. DOMB: We talked about that

10 earlier today. No, I think funding should be

11 made available to both.

12 MR. BATCHELOR: I would like to

13 emphasize even more what you said about the issue

14 of training. We appear to be talking

15 psychosocial in particular. We need more funds

16 for training psychosocial workers, and that does

17 not mean only psychiatrists, psychologists; that

18 means the full range of people from street

19 outreach, people who work with family systems,

20 people that work in hospitals, social workers

21 particularly working in hospitals, both with

22 staff and with people as they leave the

23 hospital.

24 There's really money from the National

1 Institute of Mental Health to train health
2 officials, and APA has the grant to do that. But
3 it's not enough. It's getting less and less and
4 less. And, yet, the need is growing more and
5 more and more. As we talked about more
6 counseling needs, more testing plans, et cetera,
7 we train a lot in our program, a lot of people
8 have gone through the CDC test counselor
9 training. And they acknowledge that that's not
10 enough. You're so cruel, Al, just to call it the
11 minimal training. But that's cruel but true.
12 They want more. They don't have an
13 understanding, and they recognize they don't have
14 enough time in those fifteen minutes.
15 We all know if we look at health care
16 professional practices that fifteen minutes out
17 of a physician's time to give counseling is not
18 going to happen. The physician is going to say I
19 maybe can save a life in fifteen minutes, I'm not
20 that great a counselor, even though I'm supposed
21 to do everything and I'm licensed to do
22 everything, that's not what I can do.
23 MS. DOMB: In fifteen minutes you
24 might get a person who has no AIDS education

1 except hearing the government's message on TV.
2 MR. BATCHELOR: I think the issue
3 of training is very important. HRSA's training
4 for health care professionals, which tends to be
5 not the greatest training in the world because
6 it's based on the medical model and most of the
7 trainees are not physicians. And this is not a
8 factual disease; this is a very psychosocial
9 disease, even though there are factual germs and
10 factual infections.
11 And let me add one short personal thing,
12 not to apologize, but to explain some of my
13 points of views where I seem to be Pollyanna.
14 I've been living with HIV for a long time, and I
15 was focusing on my death for a long, long time.
16 I decided I better turn that around and decide
17 that this glass is half full. That comes across
18 in other things, and I tend to see the positive
19 in things, and I hope that makes me live longer.
20 That doesn't acknowledge the fact that half of
21 this glass is empty, and I don't mean to offend
22 anybody.
23 MS. STRAWN: The thing around
24 counseling, besides emphasizing that testing

1 should not happen without counseling, you folks
2 need to say what counseling is, and what are the
3 qualities of people who can do this.
4 DR. ROBERTS: Why don't you say
5 that?
6 MS. STRAWN: Well, it's a power
7 relationship. I think the difference between
8 what people call counseling and what they are
9 really doing has to do with power. I think that
10 anyone, if they shut the door and sit down and
11 talk with a person and say they are doing
12 counseling, but I don't buy that. I think that
13 we talk at people. I think that a lot of health
14 care professionals talk at people and call that
15 counseling.
16 In counseling, the job of the counselor is
17 to help the person have enough information to
18 make an informed decision for their own lives,
19 what's good for their own life. So I would like
20 to see more standards of counseling in force.
21 Working in an alternative test site, I was doing
22 the quarterly reports. Nobody ever asked me in
23 order to get my money what were the
24 qualifications of the counselors and how much

Counseling Standards

1 time were they spending with people and so forth
2 and what kind of referral sources did they have
3 for the folks who test positive. So there are
4 some standards that have to be locked into some
5 kind of enforcement or quality control.
6 MS. DOMB: And goals for different
7 pre- and post-test counseling.
8 DR. ROBERTS: I just suggest when
9 we get to the question of what is the best way to
10 insure that minimum quality standards are met in
11 the counseling system, that is another whole
12 complicated question about whether or not
13 enforcement or incentives, what's the best way to
14 think of this as a quality management problem. I
15 just don't want to resume that regulation is the
16 only alternative way to meet that.
17 DR. FORSTEIN: Two simple points.
18 One is that in Massachusetts when we devised the
19 alternative test site system we had a fairly
20 extensive plan for counseling and supervision of
21 counseling which ensured that since most
22 counseling was going to be done by non-mental
23 health trained people there still needed to be
24 some people who had clinical expertise and

1 experience to help sort out the difference
2 between counseling and more severe problems that
3 could occur in that acute setting. That was cut
4 from the budget because it was too expensive.
5 I think if we talk about standards of
6 care, there needs to be an emphasis on the kind
7 of soft scientific stuff that goes in support of
8 counselors monitoring, not just of what is being
9 said, but whether the counselors are getting
10 sufficiently trained and supervised, sorting out
11 who is really going to have trouble and who is
12 not. The problem with that is that needs to then
13 go to people who have experience and who are
14 trained to teach the supervisors.
15 I would suggest one of the major things
16 the Commission could do is to be a very strong
17 voice that every level of governmental
18 intervention, that every task force, that every
19 conference have some emphasis on psychosocial
20 issues. You are fighting an uphill battle which
21 is anti-mental health. How many mental health
22 professionals on the Commission? How many mental
23 health professionals are in each of the
24 governmental agencies that are determining which

1 grants get funded or not? There is an intrinsic
2 bias. The mental health people just complicate
3 the waters, and we do. But somebody has to. And
4 it seems to me that there is a bias from the top
5 that mental health people confuse the issue.
6 I think Walter's designation is right,
7 that they are not all psychiatrists, social
8 workers. But it seems to me people on the street
9 dealing with people in real crisis can't be
10 expected to do street outreach work and not have
11 support so that if somebody needs to be
12 hospitalized, if somebody needs to have suicidal
13 stuff contained, that they are not out there
14 alone. There needs to be a continuum of care for
15 people who are doing the front line mental health
16 work, which is really taking place on the
17 streets.
18 There can be no stronger voice than from
19 this Commission to keep hammering away for the
20 need for every conference, for instance. We just
21 submitted a proposal, NIMH is now taking money
22 which the American Psychiatric Association had as
23 a grant to teach mental health professionals.
24 That has now gone from a grant to being hooked up

1 to medical ECTs, where training is done for
2 medical purposes, all psychosocial training has
3 to be done now in the context of medical
4 conferences. So we now get in a two-day
5 conference an hour of psychosocial training for
6 medical training. That is what is happening to
7 funding and resources. There is a wearing down
8 of the funding and the RP is for purely
9 psychosocial neuropsychiatric stuff. That could
10 do the same thing with drug addiction, substance
11 abuse and whole addictionology which we need to
12 keep very much focused on here.
13 DR. ROBERTS: Other views because
14 as Mindy said we're getting towards closing
15 time. We have about 40 or 45 minutes. Things
16 people feel strongly about that they would like
17 the Commission to hear?
18 MR. KESSLER: This is a slight
19 diversion and it's coming back to a few of the
20 things we talked about this morning about
21 financing, but it's the will and the way issue.
22 We always dance around the information or the
23 knowledge that it is going to cost a lot of
24 money. And it's important, as leaders in our

1 community, and important to support the leaders
2 at a higher level, that to enable them to talk
3 about how much money it really is going to cost.
4 Not to nickel and dime us to death and to stop
5 putting those little tiny bandaids on here and
6 there.
7 Another metaphor is we've got a
8 Frankenstein that's covered with these little
9 tiny bandages, and he's lumbering around trying
10 to stay upright. But the glue is drying out on
11 those bandaids. It's getting soft and
12 wishy-washy.
13 I brought over --
14 DR. ROBERTS: Larry, that is the
15 most mixed metaphor.
16 MR. KESSLER: The San Francisco
17 model and the collapse of the San Francisco model
18 is a perfect lesson in terms of the kinds of
19 dollars. They just finished their task force
20 report, and their estimate is that they need $310
21 million for the City of San Francisco.
22 DR. ROBERTS: When you say the
23 collapse of the San Francisco model --
24 MR. KESSLER: In the sense that

1 it's not meeting the needs of the growing
2 numbers, the diverse populations, the burnout of
3 staff, volunteers, other human resource
4 questions, and so on. And, yet, here is a city
5 that has done, relatively speaking, a lot more
6 than most other cities. To take $310 million for
7 San Francisco and butt it up against Boston which
8 has one-fifth the number of cases but 1/35 the
9 funds. And that's what New York is doing and
10 other places. They are not committing enough
11 bucks so that there they are never off of home
12 plate. They never even get to first, let alone
13 second base, because they never even plan, they
14 didn't conceptualize, they didn't cover all the
15 laundry lists in some way or another. They
16 didn't figure out how the circles intersect with
17 one another and overlap.
18 But this is the kind of example of even
19 when you try to do more, it isn't enough. It
20 won't do it, either. The $310 million for San
21 Francisco probably is inadequate, if they ever
22 found the money, and they are actually very
23 close. They're only 137 million short. But that
24 is more than most states are spending on AIDS.

1 DR. ROBERTS: And what's the
2 implication, Larry?
3 MR. KESSLER: The magnitude. We
4 really aren't addressing the magnitude here in
5 terms of actual dollars. Yet, we don't seem to
6 have a problem talking about the magnitude of the
7 defense dollars. If there is a new weapon
8 system, we throw around those numbers like they
9 were nothing. But when it comes to saving
10 peoples' lives or leading to prevention, or
11 creating a defense model around AIDS, we can't
12 afford that, there's no way. And we've heard it
13 on the trail. The Commission has heard from
14 county commissioners, from mayors, from city
15 council people, we can't talk in those numbers.
16 DR. ROBERTS: Are you suggesting
17 that --
18 MR. KESSLER: We have got to also
19 stir that caldron and put some fires under
20 peoples' butts to get on with finding the
21 dollars, or at least understanding that bandaids
22 aren't working because the tendency always is,
23 and we fed it, as Jeff said, we all made those
24 mistakes for settling for less because even in

1 our own minds we always thought this would go
2 away by 1985 or surely will go away by 1990 and
3 those bandaids would have paid off, but it hasn't
4 and they haven't.
5 And we have to sort of deal with that in a
6 kind of -- we need our own level of conversion
7 here to say let's convert the money tables, too,
8 and really talk about those big bucks. That's
9 very difficult because that means more doors get
10 slammed in our face even faster. But it's part
11 of the planning and part of the consciousness
12 raising that isn't taking place. It's the other
13 side of the compassion, the cash side of it is
14 fairly high. Very, very high.
15 MR. BATCHELOR: And the human, from
16 the health care worker's side of it, so many of
17 us, honest to God, well, this has got to be over
18 soon; surely they'll find something. We make
19 tremendous progress medically on AIDS, and, yet,
20 we don't have these great cures or preventions
21 yet. And people are just getting so overwhelmed,
22 I'm sure the Commissioners have heard that all
23 over the country, too, but those of us who
24 thought surely this would be done by now are on

1 the down side. People get burned out. That's a
2 great number of people to draw from, but we die.
3 You can't count on these AIDS victims to stand up
4 when you need them.
5 It puts a tremendous pressure on the
6 system of volunteers and workers, people who are
7 working at rotten wages and stuff like that, to
8 provide necessary mandatory services.
9 DR. ROBERTS: I hear one of the
10 things you're saying is to some extent it's been
11 the people with the calling who have, to some
12 extent, buffered the federal government from the
13 consequences of its own underfunding?
14 MR. DALTON: Subsidized it.
15 MR. BATCHELOR: Those thousand
16 points of light.
17 MS. DIAZ: That was one of my
18 concerns in bringing up, Joe, you were out, the
19 demonstration projects because really the real
20 cry around this country, not only of the four
21 that are just about to come in with the results,
22 but of the new ones that are funded, is what
23 happens after the demonstration? Where are the
24 bucks that will support the systems that these

1 people identify in terms of gaps and resources
2 and the balance of professionals that we need?
3 And the answers aren't there. And some of us are
4 getting pressure not only locally, but in the
5 horizon when we say what is the real commitment
6 of the Public Health Service of this country for
7 service delivery around AIDS. It's just not
8 there.
9 MS. AFFOUMADO: I think it's
10 amazing that we're still talking about it.
11 MR. McEVOY: I had a real
12 fundamental question, using the word early
13 intervention, we do it because maybe we can
14 extend life. We also hear the fact that there
15 are some very interesting things we are shooting
16 for which in fact five or six years down the road
17 that people actually have a chance to live
18 through this crisis. The question of where is
19 our obligation to keep quiet and not allow people
20 to take an interest and maybe giving them the
21 opportunity of survival. Do we keep quiet and we
22 basically discard them? As a human being, where
23 is my obligation to another individual to keep
24 quiet because it's a sensitive issue because

1 maybe people don't want to fund it.

2 And we talked about the Machiavellian

3 model, but maybe what we should do is create such

4 an overwhelming demand that we bring the whole

5 country to its knees. And it's the other

6 extreme. I think for somebody who is affected by

7 it personally, some of it, it's nice to sit here

8 and talk about the crisis that looms, but what

9 about the immediacy, sure I can talk about my

10 life, but the empathy of really seeing what's

11 happening to other people about me. Do I just

12 close my eyes and say, well, again, the system

13 isn't there to advise you, so I'm not going to

14 advise you to get a test which might basically be

15 the opportunity for survival? What obligation do

16 we have knowing what we have today to the

17 American people?

18 There are many people we talked about,

19 whatever course of action we take, there are

20 going to be people who are unfortunately not

21 going to survive this, any route that we take.

22 What obligations do we have?

23 DR. ROBERTS: To those who are at

24 risk?

1 MR. McEVOY: Knowing what we have
2 today, in many cases, early detection, early
3 intervention, there are things that can extend
4 life, and why would we be wanting to extend life
5 because there is a possibility of getting through
6 this crisis because scientific evidence is
7 telling us that maybe in five or six years there
8 is hope.
9 Knowing what we do know, what obligation
10 do we have to people to informing them that there
11 is a possibility that you can survive this if you
12 go through the various processes? Part of that
13 is we talked about the social model, not always
14 do you need necessarily to be tested to start
15 doing things for yourself that will help. Good
16 nutrition, reducing drug intake, reducing stress,
17 without taking the test. Those things put you in
18 a good line to extending your life.
19 The other thing is -- and that's part of
20 the social model before you go through testing.
21 The other issue is, one, you have been tested and
22 your T-cells are in a certain range, it's proven
23 the possibility you can extend it even more.
24 What obligation do we have to put back in place

1 for people, or do we have none?

2 DR. O'NEILL: There is an attitude

3 I hear not in this room but I hear it sort of out

4 there and have for awhile is that when you talk

5 about early intervention, early intervention is

6 discussed, when you talk about the medical

7 aspects, actual just medical aspects of early

8 intervention, there is a sense that someone that

9 is HIV positive does not, is not, does not really

10 have a medical condition.

11 In other words, we think of medical

12 conditions that we are morally compelled to

13 treat, we tend to think, it's easier for us to

14 think of things that are very obvious, like

15 pneumocystis pneumonia or broken leg or something

16 we can see. When we're talking about a medical

17 condition that's just diagnosed on the basis of a

18 serologic test, in some minds that's a fuzzier

19 condition. And I think there can be a sense that

20 because that's a fuzzier condition, we may not

21 have the same moral obligation to treat it as if

22 it was clearly a treatable, clearly something

23 that was an obvious, diagnosable to the visible

24 eye condition.

1 I just think we have to be very clear and
2 make no mistake about it, that with what we know
3 now medically, that the condition of being
4 seropositive for the virus, for some people, is a
5 medically treatable condition no different than
6 any other medical condition. And the analogy I
7 would make, I think that we have a tendency and
8 compensity to go around and say AIDS is like this
9 disease, AIDS is like that disease. That clouds
10 our thinking.
11 But if you take the example of syphilis,
12 for example, when you talk about treating
13 syphilis, we treat syphilis on the basis of a
14 serologic test. And somebody comes into my
15 office with a positive serologic test for
16 syphilis, that is a treatable condition, whether
17 or not they have an obvious disease.
18 DR. ROBERTS: Let me push you one
19 second. Given what's happened in Arizona and
20 Oregon in recent years where state funding for
21 organ transplants or other treatable conditions
22 has been withdrawn under the state Medicaid
23 programs, is it, where do you reach the
24 conclusion that society accepts the obligation to

1 treat every medically treatable condition?

2 I mean, it seems to me that was the

3 premise in your argument, that at least some of

4 society's behavior is inconsistent with.

5 DR. O'NEILL: I am not really in a

6 position to make necessarily an argument. But I

7 want to be clear that this is just speaking as a

8 physician, that this is a medically treatable

9 condition. If we as a society elect not to do

10 that, we ought to be clear about what we're

11 electing not to do.

12 DR. FORSTEIN: I think Jim raises a

13 very fundamental question. It has to do with the

14 difference between being able to help people

15 learn what there is that they can do to treat

16 themselves and get treatment for a condition that

17 is a medical condition but for which there are

18 other than medical treatments. And what it would

19 mean in terms of the long-term ethics of holding

20 out a test as the entrance to a system that then

21 for many of the people does not follow through

22 with what it would take to do what we would like

23 them to do.

24 I think if you're talking about the

1 testing, I'm not opposed to continuing to offer
2 testing when it leads to treatment and, in fact,
3 one of the things that we do best is to help
4 people use the test to generate treatment and all
5 that. But I think it's also unethical to say to
6 somebody, since you're pregnant, go get maternal
7 infant care to increase the likelihood of your
8 baby surviving, but there being no place for that
9 person to go. I think the dichotomy between what
10 we ethically have to do in one moment and what we
11 ethically do down the road have got to be
12 consistent in some long-term vision.
13 I think it's just as cruel to say to
14 people go get tested, and then if you're
15 positive, we'll pay for the first T-cell test to
16 tell you that you'll be eligible for the AZT that
17 we won't pay for, and this is not for people
18 without insurance. I have patients that have
19 enough insurance to cover their T-cells and
20 doctor's visits, but only 80 percent of their
21 AZT, none of their psychotropic medications that
22 they need, and they can't afford treatment, even
23 with health insurance.
24 Is it ethical for me to encourage a test

1 which leads to a recognition of a condition for
2 which we have some treatments for some people? I
3 think that rather than take a kind of yes or no
4 view of testing, we need to always put in the
5 context of does the test enable a person to get
6 the kind of care that would facilitate prolonging
7 life, both in medical and psychological way.
8 DR. ROBERTS: Isn't the ironic
9 implication of that, however, that you wind up
10 urging testing for middle class people who have
11 insurance and who can afford care, not urging
12 testing for non-middle class people who don't
13 have coverage and can't afford care?
14 DR. FORSTEIN: That's exactly what
15 we have done as a society, but no different from
16 what we have done for every other medical
17 condition. I am suggesting we have a greater
18 ethical responsibility to put in place basic
19 health care delivery system.
20 DR. ROBERTS: I was asking a
21 slightly different question. You had said is it
22 ethical to urge people to have tests in the
23 absence of care. And I'm saying to you until we
24 take care of getting a different kind of delivery

1 system in place, if you answer yes to the
2 question you asked, it's unethical to urge people
3 to have tests if they can't get care, doesn't
4 that imply that we limit testing to the middle
5 class who can then afford to get care?
6 DR. FORSTEIN: I think that's
7 exactly what's happening. I think that's why the
8 emphasis on testing is a misplaced emphasis. I
9 think it should be on basic health care delivery
10 so everyone can benefit for testing.
11 MR. DALTON: The problem isn't just
12 testing. If you look at any given early
13 intervention, there is something about
14 allocation, AZT, clinical trials, for those who
15 can get into them. Insofar as we have the tools,
16 how do we make them available to everyone? But
17 assuming that Jim's point really was a little
18 different, it wasn't at the level of politics, it
19 was the level of an individual, I'm sorry I can't
20 do anything to help you, help yourself until we
21 have X number of systems in place, are you going
22 to say to an individual, I'm sorry, you have a
23 full-blown AIDS diagnosis. As long as you're
24 walking around seemingly well, we can't help

1 you. Or are you going to help them help
2 themselves?
3 I think there is a very concrete
4 illustration that Rona talked about yesterday and
5 today. Except we're talking about people who are
6 somewhere in between those things, people who are
7 HIV positive but asymptomatic. We don't know
8 what to call them, ill or well.
9 Joe talks in terms of treatments
10 available, but that is sort of true or not true.
11 Maybe there is for a given person treatment like
12 Pentamadine until their T-cell count is below
13 200, but Jim says there are other things you can
14 do for them to help them deal with things, like
15 maybe their nutrition, or having to think about
16 dying, or not having to think about that alone.
17 We want to in a medical kind of frame call that
18 treatment, otherwise we don't care about it.
19 This gets played out in the law, of all
20 things. People can't get Medicaid in various
21 states unless they have an AIDS diagnosis. You
22 can't get into certain parts of the social
23 service system until you have an AIDS diagnosis.
24 It was a very kind of restricted image. There

1 are a number of things we can do for people short
2 of an AIDS diagnosis, some of which may help them
3 from getting an AIDS diagnosis, even if the
4 results are being Pollyannic.
5 MS. AFFOUMADO: Could I just add
6 something to what you're saying because I think
7 there is another piece of this. For many of the
8 populations that we are trying to provide "early
9 diagnosis and treatment", there are also
10 populations that you must remember have not had
11 access to health care. So they come to us with
12 many other medical problems that are not HIV
13 related, that have nothing to do with HIV.
14 For example, women have serious
15 gynecological problems that are not, that are
16 exacerbated by HIV but have been present as a
17 medical problem for them before they were
18 infected with HIV. For example, chronic PID and
19 candidiasis infections that are not HIV related.
20 Just to give you an anecdote to point up
21 something very interesting that happened at
22 Community Health Project, when we began providing
23 medical assessments in 1985 of underinsured and
24 uninsured gay men and gay and bisexual men of

1 color who also were underinsured and uninsured
2 from New York City, for many of them it was the
3 first time that they had a comprehensive physical
4 exam. And we diagnosed early conditions for
5 example, like multiple myeloma, which would
6 probably not have shown up in these people until
7 they were 40 or 50. And cardiac conditions,
8 hypertension, diabetes, forget about the dental
9 problems.
10 Now, a lot of this is really a symptom of
11 not having access to health care. And I'm not
12 minimizing what Jim is saying because I clearly
13 believe in holistic health care and alternative
14 ways of delivering services and self-help and all
15 of these things that you're talking about. But,
16 again, I want to try to bring you back to the
17 fact that these are populations that have not had
18 health care, and they are coming with a lot of
19 medical problems, not just HIV.
20 So you may not want to treat them early
21 for HIV, but you've got to treat them early for
22 malnutrition and endocarditis, and hepatitis, and
23 chronic gonorrhea that hasn't been treated, and
24 PID in women, because your therapy, your

1 alternative therapies are not going to do a lot
2 of good for them if they don't get treatment for
3 some of the things that have disseminated them
4 health-wise that are not HIV specific.
5 MR. DALTON: That's part of where I
6 was going.
7 MS. AFFOUMADO: Please forgive me
8 for being so strong on this "medical model", but
9 I think you have to understand that all of these
10 things fit into this package that the
11 psychosocial and all of these things fit into,
12 also "your body is a temple" kind of idea.
13 DR. ROBERTS: I hear you in some
14 ways saying that whatever we do about the
15 financing system, we have to do it in a way that
16 allows these multiple needs to be met.
17 MS. AFFOUMADO: Absolutely. And
18 not just say early diagnosis and treatment for
19 HIV because even though AIDS clearly is the
20 subject of this Commission, but that is only a
21 piece of it. It's again, this total
22 comprehensive thing that we've been trying to
23 talk about.
24 DR. ROBERTS: Other points?

1 MR. LEVI: There's something, I
2 think a lot of this does come back to financing,
3 but when we do keep talking about we need all
4 these services out there, something even more
5 basic is we need our Public Health Service to
6 acknowledge that even if they don't have enough
7 money to do all these things that somewhere along
8 the line this is their responsibility. And when
9 we have an Assistant Secretary for Health who
10 tells the Congressional subcommittee that
11 providing care services is not the responsibility
12 of the Public Health Service, I think we have a
13 fundamental problem, particularly when we have a
14 Health Resources and Service Administration that
15 does fund community health centers.
16 If it is not the responsibility of the
17 Public Health Service to make sure that adequate
18 services are in place, not necessarily financing
19 those individual patients' care, but at least
20 making sure that the structures and services are
21 in place, then I don't know whose responsibility
22 it is. And I think that certainly one thing that
23 the Commission can try to do is remind the Public
24 Health Service of what its original intent and

1 charter is.

2 CHAIRMAN ALLEN: Well, they'll say

3 it's the state's responsibility and the state

4 will say it's the county's responsibility.

5 MR. LEVI: I know that's what they

6 say.

7 CHAIRMAN ALLEN: And there is no

8 entitlement to health care in the United States

9 of America, period.

10 MR. LEVI: And that's a problem.

11 But there is a responsibility on the part of the

12 Public Health Service to help provide care

13 services for those who are impoverished.

14 MS. BYRNES: And the legislative

15 branch believes the executive branch has that

16 responsibility because the legislative branch has

17 been the one that's been piecemealing the

18 response together that the Public Health Service

19 implements, but it's been coming from the Hill,

20 not from the Executive Branch. That's partly why

21 it's so disconnected.

22 MR. BATCHELOR: It's a long

23 history. I worked in Public Health Service ages

24 ago. When they started dismantling the PHS

1 hospitals, Bureau of Health Care Delivery, it
2 just got the Feds out of the role of delivering
3 health care. It was in the Nixon administration
4 that this edict came down, "thou shalt not deal
5 with direct patient care". It is not a delivery
6 organization, not the Feds out of -- we're not
7 going to turn that around, I don't think, in the
8 lifetime of this Commission, or maybe the
9 lifetime of the people here. But under the
10 Constitution, basically it ends up being the
11 counties with the responsibility to deliver
12 health care. Ultimately, it follows down --
13 DR. ROBERTS: I hear Scott was
14 saying to you there is nothing in the
15 Constitution which requires it.
16 MR. BATCHELOR: But the
17 responsibility ends up basically at the county
18 level. And so if that's where the responsibility
19 is going to be, maybe that's one of the places we
20 need to place special focus on for the services
21 area. If that's where the needs are and if
22 that's where counseling and testing and early
23 intervention may be an entry point, that's a
24 place to put special focus.

1 DR. ROBERTS: We have about 20, 25
2 minutes left. Other points that people feel
3 strongly they want to put before us this
4 afternoon?
5 I assume that you guys, if we end ten
6 minutes early, you would just as soon start ten
7 minutes early.
8 MR. BATCHELOR: I can say something
9 else. I think an important additional issue, the
10 issue is that people with HIV disease and AIDS,
11 the spectrum, can contribute a lot to the public
12 policy issues, the direct service issues, et
13 cetera, et cetera. It's always unfortunate, to
14 use the kindest of terms, when people with AIDS,
15 as broadly defined, are the last to enter the
16 public policy arena and the first to be told that
17 they are not invited, et cetera. They need to be
18 the first to be invited because we have a
19 perspective, while not the sole handle on the
20 truth by any means, is a valuable, necessary
21 perspective. Without the inclusion of people
22 with AIDS and other people at highest risk
23 groups, then the picture gets distorted.
24 When CDC came up with its counseling

1 guidelines, which is an important issue for you,
2 CDC is not regulations, but guidelines for how to
3 train and how to do counseling. Those aren't
4 regulations, but they have had a profound impact
5 nationwide on what states or city or county
6 decides to use and include in their training of
7 counselors and what their requirements are for
8 the job, in fact. People don't know. How are
9 they going to find out?
10 So those guidelines are very important.
11 They have changed over the years somewhat, but
12 the early emphasis which came mostly from CDC, I
13 gather, was focused on sexual behavior change.
14 You just found out that you're tested, Mr.
15 Jones. Now I want to tell you about safe sex.
16 All Mr. Jones is thinking about is I think I'm
17 going to kill myself. His penis is not going to
18 arise for quite sometime. That penis represents
19 death to him. So now the counseling is changed
20 to focus a little more on living, on taking care
21 of yourself, on feeling the behavior change, and
22 on dealing with the shock. But had people with
23 HIV disease and AIDS been included in developing
24 those guidelines, we would have said, safe sex is

1 not the issue today; surviving this news and
2 learing to live with it is the issue.
3 So people with AIDS and HIV need to be
4 included in the policy and development process.
5 CHAIRMAN ALLEN: I want to make a
6 statement. There is a person with AIDS on our
7 Commission. I think there has been a real
8 attempt to do that. But as part of the
9 counseling, I'm humored by the fact that somebody
10 comes in and tests positive, one of the first
11 things they tell you is to try to lower your
12 stress level. I think that's classic.
13 MR. DALTON: I have one other
14 response. A lot of people put this meeting
15 together. The person who did the most is
16 probably Jason Heffner.
17 But one point in talking about the
18 invitees, someone in the conference called and
19 said what about persons with AIDS. I guess there
20 was a talk about having somebody specific. And
21 Jason basically said that at the table there
22 would be plenty of people with AIDS who will be
23 here in their capacity like yours. I think
24 that's what is important. There are plenty of

1 people with AIDS working throughout every system
2 that we've been concerned about, and they do need
3 to be involved. In their professional
4 capacities, which are very much --
5 MR. BATCHELOR: In response to
6 that, since I am the gay man, I will speak to
7 that issue, too. There has been many, many gay
8 men in positions of power and authority and
9 responsibility dealing with health care issues
10 and dealing with AIDS who were very, very fearful
11 about disclosing the fact that they were gay men
12 and, therefore, could not tell what they know
13 would be the whole truth. Many people, I have
14 sat in many rooms with many of the people here
15 for years and they didn't know I was HIV positive
16 because I was very reasonably scared to death to
17 tell anybody. People who are finally out of the
18 HIV closet, whether or not whatever other closet
19 they might or might not have been in, but people
20 who are out of that closet get a perspective and
21 say it like no other people really can.
22 DR. ROBERTS: I would suggest that
23 Walter has provided us with a very sobering note,
24 and I think a useful note in which to come to

1 closure on this part of the meeting because I
2 think it's always risky when one talks policy,
3 financing, systems, institutions, to lose that
4 orientation that Jim also tried to stress for us
5 on the individuals and what it's like for people
6 to move through the process. And to remember
7 that that's ultimately what the system is about,
8 is the way in which it impacts peoples'
9 individual experience with their own lives and
10 coping with it.
11 Just a brief word of thanks to all of you
12 for your extreme good humor and patience and
13 tolerance over the last two days. I've had a
14 very interesting time, and I thank you for your
15 patience in putting up with my occasional
16 attempts to produce a slightly higher rate of
17 order.
18 Mr. Chairman, it's all yours.
19 CHAIRMAN ALLEN: Thank you.
20 DR. ST. JOHN: Mr. Chairman, so
21 much of this discussion in the last two days has
22 centered on our health care system in the United
23 States, many people might be interested in a book
24 called the "Right To Health In The Americas",

1 which is a comparative study of health
2 legislation in Latin American and North American
3 societies. I think you might find it a very
4 interesting book. I'm sure it's available at a
5 nominal price from the Pan American Health
6 Organization.
7 CHAIRMAN ALLEN: Thank you very
8 much. I do want to thank you for your time and
9 what you've shared with us. It's quite a bit.
10 We feel, at least I feel very overwhelmed by our
11 task, but you've helped clarify some of the
12 issues for us and that was our goal. And when we
13 get together, we're going to talk about it and
14 see what we need to take back to the full
15 Commission.
16 Everything you said is making a
17 difference, and everything you do makes a
18 difference. And, again, thank you for your
19 calling, again, as you go out among the people.
20 It means a lot to us because it makes a
21 difference to us that we know that you're out
22 there caring. It helps our task, and we do care,
23 too.
24 We'll do what we can to help stop this

1 epidemic, as I know you all will, too. Thank
2 you.
3 (Recessed at 3:00 p.m.)
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1 COMMISSION WORKING GROUP MEETING

2 (Resumed at 3:30 p.m.)

3 CHAIRMAN ALLEN: Basically, as a
4 wrap-up, we want to hear what we feel are the
5 issues that could be helpful to Jeff in putting
6 together some notes. And this desire is to be
7 comprehensive so he can put together some notes,
8 but our initial impressions of where we would
9 like to see some emphasis. And also what we did
10 not hear, Don's suggestion was excellent over
11 lunch. We also need to talk about what we didn't
12 hear and what needs to be incorporated into the
13 report.

14 So anyone can start to say what their
15 impressions of what we need to incorporate into
16 this is.

17 MR. KESSLER: It's a complex
18 issue.

19 MS. DIAZ: I heard the discussion
20 of testing outside of the context of a continuum
21 of services or a delivery system is just not in
22 the best interest of our public. And that was
23 repeated a number of times throughout the last
24 two days. And that actually, I think, according

1 to the gentleman this morning, may do more damage
2 than the benefit we expect.
3 CHAIRMAN ALLEN: Are you saying
4 that, is it testing or testing for early
5 intervention?
6 MS. DIAZ: No, no. Just plain
7 testing.
8 CHAIRMAN ALLEN: Where do you place
9 the epidimiological test and the blind studies
10 and the home studies, family studies.
11 MR. GOLDMAN: Or even tests
12 designed -- one area we didn't cover which is
13 testing solely and simply not for the purpose of
14 helping the person being tested, but for the
15 purpose of changing or affecting that person's
16 behavior to prevent HIV infection to a third
17 party. It's really not focused on that person.
18 MR. KESSLER: Testing without
19 notification, either, we didn't talk about that.
20 CHAIRMAN ALLEN: Let's work --
21 MR. DALTON: One thing that was
22 said today, in relation to Don's point, I think
23 it was said by the keynote person, Marshall
24 Forstein, is that there is this sort of a sense

1 of testing that is somehow magical when they take
2 a test and then they change their behavior, or
3 they get positive results and do the right
4 thing. They get a negative result and increase
5 the vigilence, which is going in the other
6 direction. People have a license to run.
7 And his suggestion was that's not true.
8 The testing in and of itself is not magical and
9 doesn't alter behaviors.
10 We certainly can't walk away from here
11 talking about testing, it seems to me, as a way
12 of changing peoples' behavior toward third
13 parties. In fact there is really no basis in the
14 literature for even believing that that happens.
15 We also did not talk today particularly
16 about testing for persons as far as blood
17 supply. I think there are some issues that we
18 need to address around that, including what kind
19 of counseling ought the Red Cross to be doing,
20 for example, and notifying the people who test
21 positive. What kind of referrals should they be
22 making? That's another issue we didn't deal with
23 here today.
24 I think the basic feeling was we didn't

1 talk about testing for epidimiological purposes,
2 particularly over family studies. But if we can
3 at least set those to the side, and there are any
4 number of issues around that, also, like whether
5 one should unblind studies, when in fact you
6 should find out when someone is HIV positive,
7 putting those to the side, now talking about
8 testing ostensibly for the benefit of the person
9 being tested. I did hear a strong message from a
10 lot of people, it came in different forms, that
11 that kind of testing didn't make a whole lot of
12 sense.
13 CHAIRMAN ALLEN: What you're
14 saying, for the benefit of the person in regards
15 to early intervention?
16 MR. DALTON: In regards to
17 anything.
18 CHAIRMAN ALLEN: Sometimes there is
19 a benefit just knowing.
20 MR. GOLDMAN: Why?
21 MR. DALTON: All I'm saying is --
22 CHAIRMAN ALLEN: Specifically,
23 there are people that just simply want to know
24 their HIV status.

1 MR. DALTON: Well, I'm just talking
2 about what I heard. I did hear people say, I
3 heard you ask, are you talking about giving
4 people options. But in terms of a program
5 designed to say out there to the world at large,
6 go get tested, or in terms of having priorities,
7 create incentives for testing where there are
8 some other ways to use money, don't do that
9 unless you have in place a system of options for
10 people that includes not only medical kinds of
11 things, but social and support.
12 MR. GOLDMAN: I walked into this
13 meeting with a conclusion on that issue that
14 nothing in this meeting changed. I don't know
15 whether that's because the ideology of the
16 fixedness of the conclusions or whether or not,
17 whatever.
18 But if you look at the triad of outreach,
19 and I'm going to call for the sake of argument,
20 I'm going to call HIV testing a form of outreach,
21 I think it is, and you talk about access to care
22 or services, and you talk about what I'll call
23 training or personnel or staff, let's call it
24 facilities, represent a triad. And there has to

1 be maintained a balance between that triad; that
2 the balance between that triad is going to change
3 over time.
4 At certain points in time in history, and
5 it could be a year thing, but essentially what
6 you have to deal with is within a hundred dollar
7 pot, how do you allocate that hundred dollars
8 between efforts at providing facilities, of
9 insuring access, and of doing outreach. If you
10 put it all in facilities, then the facilities are
11 sitting there and nobody is utilizing them. If
12 you put it all into outreach, then you have a
13 tremendous demand but no facilities and you have
14 to balance it, and there has to be an analysis of
15 where the adequacies are over periods of time in
16 different communities, and within either, A,
17 periods of time and, B, different communities,
18 there have to be different allocations.
19 There ought to be somebody sitting around
20 making a decision, that, gee, the problem this
21 year or the next two years is we really have a
22 problem in terms of access. We ought to scale
23 down our outreach efforts until such time as we
24 beef up the system to be able to provide

1 sufficient access. When we do that or have it
2 sufficiently in the pipe so that we can see in
3 six months it will be available, then we ought to
4 go back, and so that maybe in year one you're
5 talking about allocations of 20, 20 and 60, and
6 as that system builds up, then you move the
7 allocations around in terms of the dollars.
8 CHAIRMAN ALLEN: So you're talking
9 about two things, at least I heard, but
10 distribution of funds, a justifiable distribution
11 of funds, and that also includes planning, and
12 what the health care planning is what Al said, we
13 need health care planning and locals, and then
14 the distribution of funds.
15 MR. GOLDMAN: Right. What the
16 problem is, as I see it, in terms of the federal
17 government is that the CDC is sitting there with
18 a function of prevention and outreach and
19 surveillance, and that just deals -- access isn't
20 my problem, it says. Then you have an AIDS
21 program office that I thought theoretically is
22 supposed to deal with all of the different
23 agencies dealing with AIDS and HIV infection and
24 it's being able to say to CDC, hey, there is an

1 access problem this year or in the next year or
2 two; some of the monies ought to be shifted from
3 CDC's outreach efforts in order to be shifted to
4 HRSA to provide the additional funding for this.
5 In a rational system, that's the way it
6 ought to work. And I see no reason that we as a
7 Commission shouldn't be advocating that.
8 MS. BYRNES: But more at a local
9 level because the federal government can't say in
10 LA this is the case and in Connecticut that's the
11 case. The local communities need to be saying
12 this year access is a real problem for us. We
13 want to use our dollars that way and we'll make
14 determinations about the allocation within that
15 total pie. No monies go to the the localities as
16 a total pot for communities to identify what
17 their particular needs or priorities are, and
18 testing should clearly be one thing they might
19 want to consider, but in terms of where that
20 community is at and where the predominance should
21 go.
22 MR. DALTON: But if the dollars
23 come from CDC, then it's going to be tilted.
24 CHAIRMAN ALLEN: And testing has

1 been federally driven and services have been
2 locally or state driven.
3 MR. DALTON: Just a piece of what
4 Don said, which is whether or not testing is an
5 aspect of outreach. It seems to me there was a
6 fair amount of talk about that today, and
7 certainly a fair number of people took the
8 position that it's probably a mistake to think of
9 testing as a form of outreach.
10 It certainly is not a form of outreach in
11 every community at every time. Some people said
12 education is outreach. Some people said, no,
13 outreach is when you're talking about something
14 that matters to them, and as part of your effort
15 you also talk about HIV testing. I think it
16 varies somewhat from subpopulation to
17 subpopulation.
18 Apart from that, I think that testing is a
19 dangerous form of outreach because it tends to
20 put people in a position of having a potential
21 record, assuming it's not anonymous, of HIV
22 status without necessarily attending to the
23 social consequences of that. It particularly
24 puts people in a position of having the psychic

1 fallout of having been tested without necessarily
2 having in place counseling and support groups and
3 that sort of thing.
4 And what I heard a lot of people say here
5 is what's important is counseling. That sort of
6 testing without counseling is not a good thing.
7 If the only way to get counseling is, with
8 testing linked with it, then that's the case, but
9 you still have to be careful that the point of
10 the testing is not just to get the blood to do
11 epidimiological studies or in order to track
12 partners, which is back to Don's point. So far
13 as this is driven by CDC, it's driven by the
14 desire to track partners and count bodies.
15 And what I heard people say today is, hey,
16 let's talk about counseling.
17 MS. DIAZ: But more than that,
18 standards for that counseling because CDC today
19 would not tell you that they really have
20 absolutely excellent ways of disseminating some
21 kind of counseling resources. But as Jill said,
22 she's never been asked what is the quality of
23 that counseling, who is doing that counseling,
24 how much time is being spent on that counseling.

1 Someone mentioned briefly today there's
2 probably more control in terms of productivity
3 standards within the 330 community-based
4 centers. So I think that if you just came out
5 and said, our recommendation has said we really
6 think counseling was basically an essential
7 component of any program where testing might be
8 given, that doesn't do enough in terms of the
9 quality of that counseling, who is doing it, and
10 what are the minimal standards for it.
11 MR. DALTON: They can go to
12 Phildadelphia and see how many people you're
13 seeing. If you're spending too much time, they
14 ought to be equally able to create mechanisms for
15 assuring quality of time.
16 MR. GOLDMAN: I think that HIV
17 testing is in fact a form of outreach. You
18 certainly don't want to give AZT to people who
19 are not HIV positive.
20 CHAIRMAN ALLEN: Form of outreach
21 for what purpose?
22 MR. GOLDMAN: Access to care. And
23 the other point I wanted to make is that when
24 anybody is talking about counseling, what the

1 devil are they talking about about counseling?
2 What they are talking about counseling is risk
3 reduction counseling.
4 MR. DALTON: No, not true.
5 MS. DIAZ: No.
6 MR. DALTON: That's what maybe CDC
7 is talking about.
8 MR. GOLDMAN: That's what CDC is
9 talking about. And the kinds of things you're
10 talking about in terms of the social, legal
11 discrimination kinds of responses are nothing
12 more, I think, or can be effectively analogized
13 to simply side effects sequellae of the process
14 of access to the system that the system, if it's
15 done right, must include within it the capacity
16 to help alleviate, ameliorate or eliminate. And
17 that's of the system, which means the system
18 would include that you're talking about access to
19 the kind of psychosocial care that a person who
20 is advised that they are infected with the virus
21 needs and requires, whether it be assistance in
22 obtaining some form of otherwise available public
23 benefit or in obtaining AZT or in obtaining
24 appropriate counseling, if you're looking at it

1 from the perspective of the patient in terms of
2 that.
3 And who are you going to provide all that
4 bevy of services to? The services of making sure
5 they are on Medicaid if Medicaid is available, or
6 making sure they have access to housing, how are
7 you going to define the population that that
8 system is going to serve, except those who are
9 infected with the virus and how are you going to
10 determine who is infected by the virus without
11 doing a test? So in that sense it's part of
12 outreach.
13 MS. BYRNES: It seems to me that
14 there is an agreement of that, and could be one
15 of the things that the group could say is that
16 maybe people always initially thought that it was
17 outreach, but that clearly among the group of
18 people who were here, there wasn't agreement on
19 the fact that testing was the first step of
20 outreach. In fact, it was step 4, 5 and 6 for
21 some people, and that outreach would be telling
22 people, A, this is where you go for basic health
23 care services; B, did you know that in fact there
24 even are therapies or treatments for HIV, that

1 it's not a pure death sentence; C, why would you
2 want to consider getting tested or do you know
3 what the tests are.
4 I mean, I don't disagree with your point
5 at all. You clearly feel strongly about it. So
6 did other people. I think an interesting outcome
7 of the meeting was there was not agreement on
8 that.
9 CHAIRMAN ALLEN: And I would like
10 to go with D, and that's where outreach begins,
11 consideration of the test.
12 MR. DALTON: I think all of this is
13 what people mean by counseling, not to CDC, but
14 that's why it's important to put some content of
15 what we think counseling should mean and the kind
16 of counseling that must attend all testing.
17 Outreach is obviously a mischievous term because
18 outreach for what?
19 So in terms of our own talking about the
20 subject in our reports, we need to be rather
21 clearer about what we mean by terms like
22 outreach, which have multiple meanings and are
23 ambiguous, and terms like counseling. Whatever
24 conflict appears would dissolve if we just took

1 the time and sort of specify.

2 CHAIRMAN ALLEN: So would you

3 suggest Jeff work on a glossary of some sort?

4 MR. DALTON: No. All I mean is

5 maybe we'll use words other than that. What

6 often happens in the law is you ditch the terms

7 that become encrusted and ambiguous and find new

8 terms.

9 CHAIRMAN ALLEN: So what would you

10 suggest our recommendation be, this isn't hard

11 and fast, but the direction of our recommendation

12 for the counseling?

13 MR. DALTON: Actually, I thought

14 that Mindy Domb had a wonderful thing. I could

15 take it right off of the court reporter's tape.

16 MS. BYRNES: And Jill, too,

17 articulated about four or five things.

18 MS. DIAZ: I think one important

19 thing I heard, particularly yesterday, is that

20 counseling and systems of support for those that

21 choose to be tested or not to be tested need to

22 be locally and community-based driven and may

23 represent a whole variety of configurations and

24 are not necessarily tied to structures but rather

1 to supportive mechanisms or microcosms within
2 each community.
3 I think I heard in respect to counseling
4 that necessarily we're not talking about
5 counseling that would occur at a specific site
6 connected to testing, but that counseling about
7 the test might be available in numerous different
8 settings and not necessarily needs to be tied to
9 a facility that is testing.
10 MR. DALTON: Right. They talked
11 about going to galleries.
12 MS. DIAZ: Or street.
13 MR. GOLDMAN: I think, may I
14 suggest that I've always thought in my mind and
15 maybe that's not a good way of describing it, but
16 I've always thought in my mind the difference
17 between health education and counseling is that
18 health education is directed at a wider audience,
19 whereas counseling is essentially one-on-one kind
20 of thing when you're talking about giving
21 intervention.
22 If what you're suggesting is that before
23 we talk about HIV testing, before we talk about
24 counseling, we ought to be talking about health

1 education, then I think that you're absolutely
2 right.
3 MS. DIAZ: As a health educator,
4 may I speak about the virtues of health
5 education? Basically what we intend to do in
6 health education is behavior change. We have
7 identified a positive behavior change. For
8 example, stopping smoking. The health educator
9 in ~~whiter~~ wider audiences would give you the benefits
10 as well as the detriments of continuing to smoke
11 and so forth.
12 Within the arena of counseling, basically
13 we heard today and yesterday that the person
14 might be presented with the options and
15 consequences, as you said, for, in this case,
16 being tested and not tested. So we are not in
17 any way pushing it, a desired outcome, which in
18 health education we are, because we are trying
19 necessarily to change behavior. That is how I
20 see the difference.
21 CHAIRMAN ALLEN: In the scheme of
22 all that we heard today, what proportion of the
23 energies that our working group wants to
24 concentrate on counseling, and for Jeff's

1 understanding, do you see that as one component?
2 What are the other issues?
3 MR. STRYKER: You might sort of
4 look at some models of counseling. Someone was
5 speaking of genetic counseling. When Eunice was
6 speaking I was thinking of the notion of value
7 free counseling in genetics, that a counselor can
8 just present all the numerical information and
9 let the couples sort out between themselves what
10 kind of choices to make. It used to be a fairly
11 fetching model.
12 I think people more and more realize that
13 there is a lot more to the counseling dynamic.
14 And there was some talk around the table about
15 offering testing as an option versus a coercive
16 setting for doing that.
17 CHAIRMAN ALLEN: But do you see
18 that happening now? We don't counsel like that
19 with giving the person the option of how to live
20 their life in this issue.
21 MR. DALTON: What --
22 CHAIRMAN ALLEN: I'm saying the
23 mentality of the counseling, of the behavioral
24 change, these are the options. It's not value

1 free.

2 MR. GOLDMAN: But that's because
3 the purpose of the counseling is not to help the
4 affected individual but to change that affected
5 individual's behavior for the benefit of a third
6 party.

7 CHAIRMAN ALLEN: Exactly.

8 MR. GOLDMAN: And I'm not saying
9 that that is necessarily wrong, but I'm saying
10 that's not what's advertised.

11 MR. DALTON: Let me add to that.
12 It's either to have that individual change his or
13 her behavior for the benefit of a third party, or
14 to put the "counselors" in a position of
15 informing some third party. It seems to me
16 that's what CDC and some others mean by
17 counseling.

18 Now, in terms of the folks around this
19 room who do counseling, that's not what they
20 mean. I guess my thought, Jeff, is rather than
21 starting from models down, there is writing out
22 there about what people who are counselors are
23 doing. I mean, that is very HIV specific, what
24 do you do when someone walks through your door.

1 And in --

2 MR. STRYKER: I was particularly

3 disturbed by what the CDC official had to say

4 about "we can't have a counseling cop", as if we

5 needed a Fed in the room with the two people to

6 know what's going on.

7 It seems like there should be some basic

8 empirical indicators. I hear a lot of people

9 still getting their test results by mail, and

10 there's this old saw by now with CDC, of course

11 we're in favor of pre- and post-test counseling.

12 Well, no one has quite set out in terms of what

13 that means, do you get your tests three weeks

14 later, in person?

15 When I was tested and counseled, our pre-

16 test counseling was in a group of 75 people. You

17 came back a week later, you got your results.

18 They read out your date of birth, which is

19 horrifying, to use as a number so that everyone

20 knew how old you were, which is worse than

21 whether you were positive or not, and then you

22 went down and got your results. And you could

23 tell, it's a small town, and you could tell

24 whether people were positive or negative by how

1 quickly they came out of the counselor's room and
2 in what shape.
3 So here is a model of an ATS anonymous
4 system where everyone knows each other, and
5 anonymity is out the window. But there are
6 certain benchmarks, in terms of being counseled,
7 they could be telling us as the test moves out
8 into a test system into an STD and family
9 planning clinics, how is this working.
10 MR. DALTON: There are many number
11 of things we could say explicitly about that, or
12 maybe we want to create a mechanism for someone
13 else saying that. I think we need to find out
14 what the CDC's counseling guidelines are insofar
15 as some exist.
16 MS. DIAZ: For both.
17 MR. DALTON: For both STD clinics
18 and alternate test site clinics and see if they
19 are the same, and see if some of them are at a
20 level of generality that it allows us this range
21 of what happens.
22 MS. DIAZ: It's a state decision
23 and a local county decision as to how that is
24 implemented because there are actually places in

1 the country where the pre-counseling is done by
2 video, small ten-minute videos.
3 MR. DALTON: One step is to find
4 out what the CDC is requiring at the federal
5 level and what their explanation is for the
6 division between them and state and local in
7 terms of who dictates counseling, to look at
8 what's happening in the sort of better and worse
9 programs and make some recommendations about what
10 the guidelines ought to be that can be
11 implemented at the federal level.
12 It seems to me that the CDC can condition
13 its money for ATSs and STD money on counseling
14 that meets certain standards.
15 MS. BYRNES: So, Karlon, I'll write
16 to you and say, yes, I did it.
17 MR. DALTON: I agree, and we ought
18 to focus a bit on monitoring. The bit about the
19 cop, they have cops in Chicago, apparently. I
20 mean, in Philadelphia, seeing whether people are
21 spending too much time on counseling. It seems
22 to me they can have the same kind of cop, if you
23 want to call it that, figuring out whether
24 counselors have been trained. Certainly you can

1 have the verification of that, and what kind of
2 training.
3 CHAIRMAN ALLEN: I also think, I
4 don't know if that passed us by, but when we
5 write CDC to ask that question, I have some
6 others for CDC, but your point was well made of
7 ATSs and STD clinics. What is happening in the
8 ATSs, but what are your standards in STDs for HIV
9 counseling because we're shifting the money.
10 MR. DALTON: I think we should also
11 ask them what was the basis and what was the
12 information base on which they made the decisions
13 to start pushing in the direction of STD
14 clinics. Was that based upon evidence of the
15 capacity of those clinics to do counseling?
16 MR. GOLDMAN: I think they said
17 that was the basis of a belief that they would
18 have a higher head rate there.
19 MS. DIAZ: It's deeper than that.
20 Something that didn't come up is that much of the
21 AIDS program money within CDC has shifted in the
22 last year under STD. I think that you have to
23 understand that that in some way could be tied to
24 a decision to beef up the particular HIV service

1 within STD clinics and other --

2 MR. DALTON: Insofar as we got an

3 answer and it was implicit, it was that we will

4 get a higher rate of people who are HIV positive

5 there and presumably then we can locate more

6 partners and somehow encourage people to modify

7 their behavior to protect third parties. But it

8 had nothing to do with the fact that STD clinics

9 could provide counseling or referral.

10 All I'm saying is that I think we need to

11 get from CDC, to have them document their

12 perspective on what this money should be spent

13 for, so if we say it should be something

14 different, we can articulate different from what.

15 DR. ROBERTS: I heard them say

16 something a little different. I heard them say

17 there were different populations which were

18 accessed through the different groups. So it's

19 not simply the total number of people, but it's

20 sort of spreading the testing around so that we

21 hit different, I'm not defending it, I'm just

22 saying if we're going to characterize their point

23 of view, it wasn't just the hit rate, but it was

24 who you hit.

1 MR. KESSLER: It was also a siting
2 citing issue. When they needed to expand the
3 ATS, the next layer that was obvious were the STD
4 clinics. And they didn't have the siting
5 problems that they did have on the first round of
6 ATS sites.
7 MR. DALTON: Let me tell you where
8 my concern comes from. Jill mentioned she had
9 set up an ATS system and it was there when
10 pressure came to switch HIV testing into STD
11 clinics. In New Haven, Connecticut the STD
12 clinic and alternate test site clinic were in the
13 same building, two doors apart, in the Health
14 Department, I might add. We're not talking about
15 siting issues, we're not talking about different
16 populations particularly. And in the STD clinic,
17 there was virtually no pre-test counseling
18 essentially, and truly minimal post-test
19 counseling, no referrals.
20 The people doing the work were not people
21 who came over from the alternate test site or
22 people who were trained other than a day's
23 training roughly on HIV, and it was just an
24 additional thing to the laundry list.

1 So that at least in that particular
2 concrete example, it seems to me that the
3 justifications, that we are teasing out what was
4 said by this CDC representative, couldn't
5 possibly have played out. So it leaves me, not
6 that one example alone, willing to be skeptical,
7 shall we say, about the rationale.
8 CHAIRMAN ALLEN: Just to stop for a
9 second and say we've got about thirty minutes
10 until we need to close. I know some of you have
11 planes.
12 We have concentrated a lot on the
13 counseling issue. I want to make sure we get
14 everything we want, to emphasize it.
15 DR. ROBERTS: I have to leave. I
16 just want to thank everybody particularly for
17 putting up with my efforts to simultaneously give
18 you as much of the time you wanted and to tell
19 you how much I enjoyed this.
20 CHAIRMAN ALLEN: We have talked
21 about the counseling and CDC.
22 MS. BYRNES: And I assume that's
23 like Section No. 2 of whatever the size of this
24 report is that we talk about the disagreement or

1 at least different points of view about whether
2 to test, where tests faults on the continuum,
3 whether or not it's the first step or third
4 step. But if you choose to test or in any
5 setting where testing services are provided or
6 where HIV or AIDS services are provided, this is
7 what we understand counseling should entail.
8 These are the components and these are the
9 standards that should be in there. Does that
10 sound --
11 MS. DIAZ: A bit, except don't
12 negate the fact that it was said that counseling
13 about the test can occur outside of the agency.
14 MS. BYRNES: I agree with you
15 completely on that.
16 CHAIRMAN ALLEN: That's good.
17 MS. BYRNES: Separate from the
18 test.
19 CHAIRMAN ALLEN: And we've got
20 Don's triad.
21 MS. BYRNES: Outreach access
22 facilities?
23 MR. GOLDMAN: Yes, and I don't mean
24 the kind of education outreach. I mean by

1 outreach patient identification in terms of who
2 was going to be provided the broad outray of
3 services.
4 MS. DIAZ: In religious terms,
5 evangelism.
6 CHAIRMAN ALLEN: One of the things,
7 I'll just chime in one of my concerns, is that of
8 HRSA and the defunding of HRSA. Their evaluation
9 component of their demonstration grants, what are
10 they evaluating, whether they worked, whether the
11 money was spent properly, whether the HIV
12 infection rate decreased? I would like to see
13 that --
14 MR. DALTON: What is it that's
15 being defunded, what kinds of --
16 CHAIRMAN ALLEN: Well, I don't know
17 if we can do it outside of agency terms.
18 MR. DALTON: I'm asking, they can
19 switch around what HRSA does as against any other
20 agency. But implicit in what you're saying is
21 that there are certain kinds of services or
22 certain kinds of something that's being devalued.
23 CHAIRMAN ALLEN: Case management is
24 being devalued, health planning. So all of these

1 --

2 MR. DALTON: What else?

3 CHAIRMAN ALLEN: Home care, AZT.

4 What else? There's some others. I'll have to

5 think back. But I want to get the point across

6 that here we are without substance with early

7 intervention, and we're coming up with this

8 message. I think we need to ask HRSA some

9 questions.

10 I've got some questions I'm going to send

11 to them and their staff. If you have some

12 questions for them, maybe we can get back and

13 incorporate into some type of format for

14 recommendations. But also in relation to CDC.

15 MS. DIAZ: One of the things I

16 recommended to our newly-formed HRSA advisory

17 group is that we might want to look at the

18 results of the first four demonstration projects

19 and some other mutual issues of concern between

20 the HRSA advisory group and this subgroup of the

21 Commission, and they were very much in favor of

22 doing that. So we don't have to go through some

23 of the same --

24 MS. BYRNES: What is the time line

1 on that? When do they expect that ongoing
2 evaluation to be completed?
3 MS. DIAZ: The three years are up.
4 MR. STRYKER: There are case
5 studies, and we provided the LA case study before
6 the hearings. Those are available for all four
7 cities. They tend to be descriptive rather than
8 analytical.
9 MS. BYRNES: Is that it?
10 MR. STRYKER: That's all that I've
11 seen.
12 CHAIRMAN ALLEN: I don't think it's
13 there.
14 MS. DIAZ: No, there are certain
15 common denominators. For example, what Don is
16 asking about is how a community has been able to
17 be integrated in ongoing planning for HIV is
18 definitely an evaluative part of those
19 demonstration projects.
20 In other words, a community that was given
21 a HRSA demonstration grant and was not able to
22 get their act together and coming and identifying
23 needs, identified gaps and what it needs in terms
24 of future financing has simply not done the job.

1 CHAIRMAN ALLEN: Well, from what I
2 understand, Larry, you may have some insight into
3 this, first off I do know this: That HRSA is now
4 going to fund 16 to 18 out of the 25 they
5 started. And there is not really a clear
6 understanding of who or what criteria they are
7 going to use for that funding; and that many of
8 the demonstration money that went out has not
9 been that effective.
10 It seems that -- have you heard this?
11 MR. KESSLER: No.
12 CHAIRMAN ALLEN: Like some of the
13 RWJ grant money that went out that tried to get
14 up case management around the country, some of
15 those were dismal in the response. But I'm
16 curious of the evaluation tool. I'm curious,
17 along with moving in the HRSA questions, is what
18 are they going to do for states. If they are
19 backing off with this demonstration money, who is
20 going to pick up the ball? Who is going to be
21 the technical advisors to the states and the
22 local governments? The person coming in from
23 Missouri that is head of HRSA, before he got
24 there was state that said HRSA needs to get

1 involved with states, but HRSA says, no, that's
2 not our job.
3 MR. DALTON: Just what is --
4 CHAIRMAN ALLEN: The
5 community-based organizations that are going to
6 be funded, they are backing off. Who is going to
7 pick up that ball? Who is going to make sure
8 that's going in when there are block grants going
9 to the states and counties? There's not any
10 strings attached to that, but there isn't any
11 technical assistance to advise them or help them
12 assume the HIV leads. You can't monitor block
13 grants because it's given to the states.
14 Can you monitor it?
15 MS. BYRNES: You should be able to.
16 CHAIRMAN ALLEN: You should be able
17 to, but you don't.
18 MS. BYRNES: We don't do it in any
19 block grant program, but it's certainly possible.
20 CHAIRMAN ALLEN: Exactly. That's
21 where the problem is there.
22 MR. GOLDMAN: I think theoretically
23 it's a requirement on the part of the state to
24 give the Feds a plan as to what they are going to

1 be doing with the money but there's no way the
2 state and the Feds have any authority to say we
3 don't like what you're doing. I guess I count
4 health care monies to build, for the state to
5 build a space --
6 CHAIRMAN ALLEN: But how that's
7 utilized. HIV is not a part of that planning
8 process. So that is some of the things that I
9 think that I would like as a working group for
10 the Commission to write HRSA and say we would
11 like some answers to these questions.
12 And I think that we also have to ask some
13 questions to CDC, not only about counseling but
14 do you feel that this is an ethical response to,
15 an ethical endeavor to advertise early
16 intervention if the services aren't there.
17 MR. DALTON: That seems to me like
18 a profoundly unproductive thing to do. Let me
19 tell you why. I think asking somebody whether
20 their response is ethical, nobody is going to say
21 my response is unethical.
22 CHAIRMAN ALLEN: Okay. Let's
23 rephrase the question.
24 MR. DALTON: Secondly, I think it's

1 a mistake to try to get CDC to criticize itself,
2 however you frame it. If we find from CDC what
3 they are doing, we are in a position of making a
4 judgment about whether it's good or bad. That
5 is, we are perfectly capable of saying that
6 advertising early intervention without having
7 services in place is a bad thing. We don't need
8 them to say it.
9 CHAIRMAN ALLEN: I stand
10 corrected. I feel like a sense of urgency that
11 they are about to come out with this in two
12 months. So there is that sense of wait, stop,
13 look and listen. But you're right.
14 MR. DALTON: Let's talk about how
15 we do that, but I'm suggesting your particular
16 procedure is not the way to do it. Let's talk
17 specifically about that. Maybe as far as the
18 1990 America Responds To AIDS campaign we should
19 ask the relevant government officials to come to
20 our meeting in March, the full Commission
21 meeting, and to show us and to have an exchange
22 there which is pretty quick in the scheme of
23 things. And Maureen hasn't fallen over yet, so
24 it seems to be within the realm of possibility.

1 It seems to me the questions put to CDC
2 are much narrower than that, like what are your
3 standards for the following. For example,
4 earlier on in this meeting we started talking
5 about standards for labs, the different kinds of
6 tests. One thing that I would at least like to
7 know is is there a role that CDC can perform
8 better in monitoring what it is that labs do.
9 MS. BYRNES: I think Doctor
10 Konigsberg wants to look at that issue when he
11 looks at all of this stuff in the public health
12 context. So you may want to ask the CDC -- this
13 is an informational thing.
14 CHAIRMAN ALLEN: I just want to, as
15 a point of clarification, you're not disagreeing
16 with the content; you're disagreeing with the
17 strategy, is that what I hear you saying? The
18 content of saying we've got to deal with the
19 America Responds To AIDS and the early
20 intervention message, you agree with the
21 content. You're saying the strategy you would
22 like to see different. I agree. Instead of a
23 letter, you want to say --
24 MR. DALTON: Well, if we're going

1 to write a letter, I think it should be different
2 than that, but I think we should bring it before
3 the Commission.
4 CHAIRMAN ALLEN: Anything else?
5 Those are my issues.
6 MR. KESSLER: In terms of we
7 started out earlier about listing some questions
8 we didn't deal with, did anybody say that we
9 didn't deal with the whole question of testing in
10 the military? I see that is being different than
11 testing in the civilian population, slightly
12 different because of the reasons, the actual
13 stated reason is different than prevention.
14 MR. GOLDMAN: We really only
15 discussed at this meeting instances in which the
16 stated reason for the testing was in a context of
17 care of patient being tested. And all the other
18 issues involved in testing, whether it be blood,
19 military, prisoners, immigration, prevention,
20 risk reduction, behavior changes, partner
21 notification, issues of name reporting for
22 purposes of partner notification, we never
23 discussed.
24 MR. STRYKER: I have a little bit

1 of concern because we had some people who weren't
2 able to come, we did not try and stack who was
3 around the table. But it seems like part of the
4 consensus that what our moderator was nervous
5 about was an artifact of people from urban
6 centers who had a lot of agreement about what
7 they were up to.
8 My sense is that the testing juggernaut is
9 really picking up speed, whether it's the test
10 moving out of ATS into other sites, or physicians
11 wanting the test to be incorporated more as a
12 standard battery of tests and treated more like
13 CBC or other normal blood assays, and partner
14 notification. I think Marshall, of all the many
15 metaphors we were treated to, I think Marshall's
16 one of the test as a lightening rod I think is
17 something we have to face as a reality because
18 it's certainly a focus of a lot of legislative
19 action, and it's a focus of a lot of public
20 health strategies and some stuff we didn't get on
21 the table.
22 I think some of them are already loose
23 issues. Whatever the rationale behind the
24 military issue is, it's underweighed and there's

1 not much you can do about it except to learn from
2 it, maybe. But there are other features of
3 testing that we weren't able to take up.
4 MS. BYRNES: Again, those things
5 will be helpful, I think, to some of the issues
6 that Doctor Konigsberg wants to look at in
7 helping him identify what are the issues that
8 perhaps could be discussed or looked at in
9 another context.
10 MR. DALTON: Could you tell me?
11 CHAIRMAN ALLEN: In what form?
12 MS. BYRNES: Doctor Konigsberg very
13 much wanted the participation and presence of
14 public health officers so that you got the view
15 and the perspective of the local and state public
16 health officers. And I think --
17 MR. DALTON: To deal with what
18 issues?
19 MS. BYRNES: Testing would be one,
20 a big one.
21 CHAIRMAN ALLEN: The one?
22 MS. BYRNES: Big one, there are
23 others.
24 MR. DALTON: Diane Ahrens' group, I

1 thought hers --

2 MS. BYRNES: We looked at mayors,

3 county officials, and at the entire epidemic, not

4 just particular issues that public health

5 officers most recently and historically have been

6 --

7 CHAIRMAN ALLEN: But explain what

8 form. Are you talking about a full Commission

9 meeting?

10 MS. BYRNES: It's not clear. He's

11 talked to the Chairman about the possibility of

12 another working group looking at, among others,

13 testing as an issue with a variety of public

14 health officers.

15 MR. DALTON: It seems to me to talk

16 about testing or any of the other activities, in

17 a context of which the meeting is predominantly

18 or solely public health officers is absurd. It

19 seems to me if we are worried about having a

20 meeting addressing the same issues that is

21 dominated by, let's say, community-based service

22 organizations, it seems to me it's the same

23 phenomenon.

24 MS. BYRNES: But, Marion --

1 MR. DALTON: Which is why we wanted
2 Konigsberg to be here at this meeting.
3 MS. BYRNES: And planned on being
4 here, and so did Fred Wolf. For whatever reason,
5 some of those people were not able to be here.
6 MR. DALTON: Fine. I'm saying that
7 to simply have public health officers talking
8 about what policies should be with respect to
9 reporting or epidimiological concerns or testing
10 is absurd.
11 MS. BYRNES: My suggestion would be
12 that this may be a discussion you want to have
13 with Doctor Konigsberg and the rest of the
14 Commission in March when you report on what
15 happened here, what's the outcome, what do the
16 rest of the Commissioners feel what needs to be
17 done.
18 MR. GOLDMAN: Why is it absurd?
19 What's absurd?
20 MR. DALTON: What is absurd about
21 it is --
22 MR. GOLDMAN: What is it that's
23 absurd?
24 MR. DALTON: I was going to say it

1 is absurd because --

2 MR. GOLDMAN: No, what is it that's

3 absurd? What are you referring to?

4 MR. DALTON: Having a meeting,

5 having a working group of just public health

6 officers.

7 MS. BYRNES: I don't want to

8 misrepresent him. He may also think it may be

9 appropriate to have other people there as well.

10 (Off the record).

11 MR. DALTON: Putting together Don's

12 comment and Maureen's comment, it seems to me

13 when we report to the full Commission what we

14 ought to say is we wanted a meeting in which

15 people with different perspectives on the problem

16 were in fact represented; that -- and indeed we

17 invited people with that in mind; that people who

18 bowed out seemed to have different perspectives,

19 that we want to fill in that perspective. But

20 our sense of these issues that they are ones that

21 we have to need to hear people from a variety of

22 perspectives on, which is the point I'm making.

23 MS. BYRNES: I'm with you. I don't

24 want you to feel that I'm suggesting something

1 different.

2 MR. DALTON: I'm saying I think we

3 can reflect that in our report; that is,

4 indicating the shortcomings of this meeting is

5 taking on ourselves the very same point I'm

6 making.

7 MR. KESSLER: I don't think it was

8 necessarily a mistake that they weren't here. I

9 think in part those who were here, there were a

10 couple of public health people here, don't like

11 dealing with the menu that we dealt with. They

12 like to simplify it. Their focus is much more

13 easily put and simplified by saying we're

14 protecting the public health, and they talk about

15 transmission or whatever.

16 But we were talking about psychosocial

17 issues. How many public health people talk about

18 psychosocial issues of testing? They talk about

19 prevention and epidemiology and surveillance.

20 And you can read it on the face of Denman Scott,

21 that this was superfluous as far as he was

22 concerned. Al Plough got in because he's a

23 planner and public health person.

24 MR. DALTON: I'm glad you mentioned

1 that, that we did have some public health people
2 here, including ASTHO.
3 CHAIRMAN ALLEN: And John Ward is
4 of the public health realm. He's been a public
5 health officer for a long time.
6 MS. BYRNES: And Joe O'Neill.
7 CHAIRMAN ALLEN: If they want
8 another meeting, that would be redundant.
9 MS. DIAZ: A focus on another task
10 force may be very devisive. It certainly could
11 put us in a situation of this Commission having a
12 public health task force with a view on testing.
13 I think if this same group has to hear additional
14 input from the CDC and public health officials,
15 it would be very interesting and complimentary in
16 many ways.
17 MR. GOLDMAN: I think we can
18 effectively say, and if we carefully limit what
19 we say, I think we can effectively say that where
20 and in those circumstances that the primary
21 purpose, thrust, advertised goal and everything
22 else of testing is in fact to provide an avenue
23 for access to services, that it is a mistake to
24 do so and to set up a program without first

1 insuring that there is some kind of reasonable
2 access; that that has a certain basis both in
3 terms of fairness and equity as well as in terms
4 of common sense. It's silly to put resources
5 into an effort that's designed to promote access,
6 if in fact the facilities aren't there to
7 access.
8 And, so, whatever perspective you may look
9 at it from, if that's where you're coming from,
10 then you have to insure that there has to be some
11 reasonable levels of access before you use that
12 as the basis.
13 MR. KESSLER: I would like to amend
14 that a bit in that using your approach, you can
15 also, in addition, then do surveillance and
16 epidemiology.
17 CHAIRMAN ALLEN: Sure.
18 MR. KESSLER: Whereas sometimes
19 it's reversed. But when you reverse it, you
20 don't necessarily do the other.
21 MS. DIAZ: I think we ought to get
22 into the final record that a couple of people
23 made statements about their desire or wish that
24 by creating a greater demand for testing that

1 this might drive a creation of a system of
2 delivery and response. And I think that has to
3 be mentioned because we can't just close the door
4 to that particular option.
5 Some people believe that by creating such
6 a large demand for testing services, that that in
7 fact may drive government, local groups and
8 health systems to develop. It was said and I
9 think it has to be represented. I'm reflecting
10 what was said. I'm not necessarily saying that's
11 my point of view, but I don't want that to get
12 lost.
13 MR. GOLDMAN: My response to that
14 is that given limited resources, that it seems to
15 me a higher level of priority to insure the
16 access, to put money into and to improve access
17 to facilities for those who you are in fact
18 testing rather than to seek to test more and
19 create more and deliberately not putting money
20 into the services that are provided to those who
21 in fact were tested. And that that as a -- and
22 that it is a cruel and inhuman political use of
23 people to use them in that way as a political
24 device which is simply wrong and, as far as I'm

1 concerned, immoral.

2 CHAIRMAN ALLEN: But we need to

3 address what I hear Eunice saying, and that can

4 be a response, but that needs to be at least

5 addressed.

6 MS. DIAZ: I'm saying there were a

7 number of people here, and I heard it over the

8 two days, and they said it not only publicly but

9 also separately to us that they are hoping that

10 the hope is that by creating a great demand for

11 testing services, this might push the whole

12 program of early intervention or access points

13 through the health delivery and a response system

14 at the local level for deliverance of that, or

15 meeting that demand.

16 MR. DALTON: And there are a

17 difference of opinions among people around the

18 round table about whether that was a good idea,

19 bad idea, a workable or not workable idea. There

20 was a fair amount of discussion around that, and

21 we certainly need to reflect that.

22 I just want to say one other thing that

23 doesn't follow from that. It was suggested

24 earlier, I think by Larry, that we never got to

1 issues like partner notification. I'm not sure
2 that's true.
3 Jeff, you should take a look when you look
4 through the many volumes of the record of this
5 meeting, the extent to which people talked about
6 that explicitly. But it seems to me it was
7 certainly implicit in a lot of what people had to
8 say; that is to say, people were saying in
9 effect, we don't think testing should be used
10 simply to drive something like partner
11 notification; we think testing should be used to,
12 as an access point for care, for psychosocial
13 care and medical care.
14 I think that this working group needs to
15 tease that out and to talk more explicitly and at
16 greater length about partner notification and
17 HIV, mandatory HIV reporting. But I think this
18 is part of the same set of issues that we've been
19 talking about for the same two days, somewhat
20 buried, but somewhat there and implicit. I don't
21 think this is an issue that gets split off from
22 the issues we've been talking about and should be
23 dealt with solely by public health officers
24 looking through that single perspective.

1 CHAIRMAN ALLEN: I think that we
2 can tap into that with Alan Hinman's testimony
3 and Jeff's questioning about the funding and how
4 much is going into partner notification as
5 opposed to other services.
6 MR. DALTON: Which is, by the way,
7 one of the questions we should follow up on.
8 MR. GOLDMAN: I think, Harlon, the
9 objections that we heard to the partner
10 notification was not that partner notification
11 was inherently bad, but rather that partner
12 notification ought not to be viewed as being a
13 counseling service to the HIV positive person who
14 is under care.
15 CHAIRMAN ALLEN: Or driving the
16 system.
17 MR. GOLDMAN: And that there may be
18 a different purpose involved, a different
19 function involved, and it is just simply not part
20 of that care and service.
21 MR. DALTON: You're right. And I
22 was much to imprecise. My only purpose for the
23 comment was that we were talking about partner
24 notification, at least its relationship to the

1 other things we were talking about. And I don't
2 want to give up partner notification and
3 mandatory HIV testing as our concern simply
4 because we didn't deal fully with the issue this
5 time.
6 MS. DIAZ: I have one thought
7 before I go, but I don't think we've said
8 anything for the final record about the concern
9 expressed by Marie and Romeo and others about
10 what testing may mean by the government or
11 encouraged by the government to disenfranchised
12 and minority, racial and ethnic populations, who
13 are many times living from day to day, looking at
14 how they can survive, in terms of poverty, food
15 needs, child care, and other kinds of priorities
16 that a person in a certain socioeconomic status
17 in this society may have to just for the sake of
18 survival be concerned about many other things.
19 Testing may not be a priority or may not be
20 viewed with the same emphasis.
21 And the fact that the government is
22 encouraging that person or looking over to see
23 that they get tested actually may send even more
24 resistent signals or put up many barriers, this

1 is what we're interested in, are you going to be
2 tested, versus you don't have food on your table,
3 or there is no place to take your children to go
4 to a clinic yourself.
5 So there are many other priorities in
6 terms of disenfranchised populations in viewing
7 the whole test. I think Marie said that.
8 MR. GOLDMAN: I think the important
9 thing that was said there, or that I got out of
10 it, was that it ought to be those communities
11 that make the decisions as to what to do. And it
12 may well be that a given community may well make
13 a decision but the most important thing is not to
14 do any HIV testing or minimally or unaggressively
15 or only on request, and all of its resources
16 ought to be put in terms of child care or health
17 care facilities in that area.
18 MR. DALTON: It seems there's
19 another practical consequence of this. Insofar
20 as we are accustomed to thinking about putting
21 AIDS money or HIV money into AIDS-specific
22 organizations or institutions, that may not be an
23 altogether sensible strategy in communities of
24 color or other places as well.

1 It may, for example, make sense that the
2 organizations within a given community that do
3 HIV counseling would be the Head Start Program or
4 the program that works in other social needs as
5 conceived of and experienced by that community so
6 that someone sitting down to talk to people about
7 their food needs or child care needs or whatever,
8 during the course of developing a relationship
9 with somebody, then may counsel about HIV as well
10 and get some HIV money because they in fact are
11 the ones who are in the best position to get the
12 ear of that person because they are talking about
13 HIV in the context of a social --
14 MR. GOLDMAN: But I think the
15 minority communities may have a difficult
16 decision to make. But I don't think they can
17 say, on one hand, that we want our fair share of
18 the AIDS money; and, B, once we get it, we want
19 to have the right to decide how to spend it,
20 including spending it on areas that are remote
21 from AIDS -- because those are the areas --
22 MR. DALTON: That wasn't my point.
23 My point was if a Head Start center or a church
24 day care center or an organization that has

1 traditionally been involved in a set of other
2 concerns that are of importance to different
3 communities says we want some AIDS money because
4 we're going to fold that into our other
5 activities, that should be something that merits
6 respect, and not simply say are you an AIDS
7 organization.
8 MS. DIAZ: In other words,
9 integrating it into an existing structure?
10 MR. DALTON: Yes.
11 MS. BYRNES: I am Maureen Byrnes,
12 Executive Director of the Full National
13 Commission on AIDS, and I now adjourn this
14 meeting.
15 (Whereupon the meeting
16 adjourned at 4:30 p.m.)
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1 CERTIFICATE

2

3 COMMONWEALTH OF MASSACHUSETTS

4 SUFFOLK, SS.

5

I, LISA W. STARR, a Notary Public in and
6 for the Commonwealth of Massachusetts, do hereby
certify:
7 That the said proceeding was taken before
me as a Notary Public at the said time and place
8 and was taken down in stenotype writing by me;
That I am a Certified Shorthand Reporter
9 for the Commonwealth of Massachusetts, that the
said proceeding was thereafter transcribed into
10 computer-assisted transcription, and that the
foregoing transcript constitutes a full, true,
11 and correct report of the proceedings which then
and there took place, transcribed to the best of
12 my skill and ability.
IN WITNESS WHEREOF, I have hereunto set my
13 hand and Notarial Seal this 20th day of February,
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14

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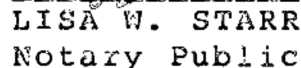

16 LISA W. STARR
17 Notary Public

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My Commission Expires: May 13, 1994.

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