NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME
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MEMORANDUM

To: June Osborn, M.D.

From: Karen Porter KP

Date: February 25, 1991

Re: Notes from February 11, 1991 Meeting

As promised, enclosed please find notes on our discussion regarding the final report. If you have questions or concerns please feel free to call Maureen or myself directly.

Final Report Discussion 2/11/91

In attendance around the table:

June Osborn	Ellen Tynan
David Rogers	Holly Taylor
Maureen Brynes	Robert Fullilove
Karen Porter	Jennifer Harlow
Tom Brandt	Pat Chaulk
Frank Arcari	Pat Franks
Molly Coye	Jane Silver
	Jeff Stryker

Introductory remarks

M. Byrnes:

- Prevention issue is least defined for the final report, we still need some input into specifics. Care, treatment, financing, are a little more well defined. Research discussion will include where we are and where we are going.

- How does the HIV epidemic fit into the social context of today, poverty, discrimination, housing, education, illiteracy. Consensus of the Commission that we want to say something, however, don't want to use overwhelming social issues as an excuse not to act.

- Themes for the final report:
  - partnership
  - leadership
  - commitment
  - investment
  - compassion
  - urgency
  - complacency

- Discussion with Molly Coye on how she can help look at the role of the public health system, different levels of government, and the private sector in education, prevention, care and treatment, and financing.

- The report will have:
  - Introduction
  - Education & Prevention
  - Care & Treatment
  - Research
  - Who's responsible for what
  - Financing
  - Larger Social Context

- Understanding that this will be the Commission's report, no one owns any of the chapters, consultants are just that. Commissioners will have the opportunity to tinker and change the document.

K. Porter:

- There have been three interim reports so far that have picked up on specific issues that have come up at the hearings. Final report will be able to take on the AIDS issue in a larger context and look at long term issues. Have the interim reports to look at issues analytically. The interim reports will make up the second of two parts of the document.

- Feedback from the Commissioners has been: What is the most effective way to get this information out? It's so urgent -- we need to keep the topic alive. It needs to be passionate and hit the issues. There are a lot of different ideas about how the report should look but not a discrepancy on what should be discussed.

J. Stryker:

- Had an epiphany on the balcony at Ft. Washington shelter before the men sleeping there had ever arrived. I have many reports on my shelves at home, need one that has heart as well as clear analysis. Karen and I have been trying to be academic about the whole process, but also realize it needs the heart, passion. We want people to hear the voices.

K. Porter:

- Privilege of Commission has been hearing from so many people, traveling broadly. Need to use hearing transcripts/site visits. Need to rely on most up-to-date scientific information and individuals with AIDS, experts. The sense the Commissioners have received through all of this needs to be in the report. We can use the "prism" idea when looking at AIDS. Think about where the Commission will enter the prism/situation. Unlike the Presidential Commission we don't want 500 recommendations. Should reflect who is listening to us. How you frame the position of the Commission is important. How we talk about the subject which we've taken on is important. Need to look at the larger social context and then make sure we don't give people an excuse on the short-range issues. The Commission is afraid of that. We need to look at long- and short-term. Need for funding and finance on two levels -- national health care and immediate efforts.

M. Byrnes:

- We shouldn't be afraid to say what the integral issues are, and also say "we do not mean the following" shouldn't dance around anything. Can be clear about stating what we mean and what we don't mean.

K. Porter:

- Don't intend to do a large number of recommendations. We'll have chapters and recommendations, but only a finite number of hard-hitting recommendations.

Who is the Intended Audience?

P. Chaulk:

- Delighted to be asked to join in the final report process, happy to hear that the social context will be addressed. We have been working on a document on gun control in which we have taken a similar approach.

  Who is the audience for the report? Is it the general public, or is it going to be keyed at a specific group? Directed towards Congress or the federal establishment?

D. Rogers:

- Short, unequivocal, hard-punching, manageable series of recommendations. So that no one can walk away. Outcome rather than process. Have a clear view of the audience -- the opinion makers. The press, major pundits -- you can't write for the president. Our interim reports keep issues on the public agenda. Need to be responsible and data based -- that can mostly go in appendix. It should be a very short report that says we're doing a crappy job out there and there's an appalling lack of leadership -- we need to do something about it. Say what's happening and what's not happening.

M. Byrnes:

- We have a mandate from Congress but that doesn't mean that all of the recommendations have to look at only what the feds should do. Recommendations don't have to be limited to federal legislation or federal appropriations. Need to look at where the pressure needs to be applied.

Message of Passion

P. Franks:

- What is your passion as a person and as the Chairman of the Commission?

J. Osborn:

- Trying to attract people's attention to the epidemic. Metaphor in my mind is that I am trying to find the tallest building and shout as loud as I can to let everyone know about the inhumanity going on and the inconsistencies in our approach to the epidemic. We are getting into the issues of throw away people. I try not to sound like an academic. Shouting for me means being passionate, not noisy, but conveying a message. If we could move the country just a little bit that will be an accomplishment and the rest will follow along. Need to fight for those without a voice, or soft voices that need to be heard.

- Both Dave and I have spoken to establishment groups. I have never had to face a heckler or any dissent. If people can hear the way it actually is we might get more of a reaction.

Role of a Commission

D. Rogers:

- Commission. Foundations always asked to set up Commissions. Do they ever do any good? Both yes and no. Commission/ report trying make a splash and be timeless/substantive. Every once in a while they capture attention and galvanize. Often times they are used over a period of years. They resurface when crises hit and something has to be done immediately.

Who's Contributing to the Final Report

M. Byrnes:

Ch. I. Historian -- Still pursuing a point person. Talking with Allen Brandt but not sure his time and his schedule will permit. Section will discuss -- where have we been? Where are we going? Prevention, treatment, research and feedback with this person and recommendation in terms of what the community should be looking at.

Ch. II. Either one chapter or three. Do we want to look at these issues separately. Pat Franks -- prevention, Jeff Stryker -- research...

Ch. III. Molly Coye. Asking "Who can and should be doing it?" The who should do it is part of the Commission. Commissioners are asking: " what is the role of the Public Health System? Who? Has it traditionally been federal government's responsibility. Than why not with AIDS? The States? Molly can identify who's responsible for action. This could be the most difficult section, because it might have to be part of each chapter. Need to coordinate.

Ch. IV. How will we pay for it? Johns Hopkins group and Dr. Davis.

Discussion of Outlines

K. Porter:

- (Going through the two outlines in your packet and showing that there are actually one in the same) Outlines are mirrors of each other but constructed differently. On the outline labeled "Document 3", things have been collapsed into certain sections. Who should be doing what, includes that federal response. Other issues include social context. Outline that everyone has in mind, have divided it up into pieces to make sure what everyone needs to know and where we are today.

- From Molly Coye's perspective we need to really think about what the tasks are. Identify the problems then the tasks and then identify the tools that will be needed.

- Discussion with Pat Franks, we should address all of the questions in reference to each issue. Task here is to agree

on what way would be the most appropriate. Today we need to leave with tools to go and get started. Be able to put it into a time line as well.

Nation at Risk/Theme for Final Report

J. Stryker:

- We want a great impact, not as someone describing a Royal Commission said, a "political niblick to get the government out of a bad lie." Nation at risk. We need galvanizing language. Something like the "act of war" section in the education report.

R. Fullilove:

- Comment and question. I was working at the Department of Education when the "Nation at Risk" report came out. The "Nation at Risk" was used as a part of each chapter heading to bring home the point. The report didn't discuss p-values and all of the other data analysis in the text. At the time people were not paying attention to minority education or focusing on the transition from elementary to secondary education. This report needs something like the prism to make it easier to write a piece of the document, need an overriding theme. Does this something exist?

P. Franks:

- AIDS is not a prism but a wedge to create action, to reform the system. Transforming health care and social service system as a result of the epidemic.

T. Brandt:

- Prism concept-- everybody likes it, but don't want to overuse it. It was already used by Watkins in the Presidential Commission on HIV Epidemic report. May have a negative connotation in the minds of some that feel it has been overused. Better to use the wedge idea -- leading us to answers. It's positive, proactive and transforming.

J. Silver:

- Some of the themes -- leadership, partnership commitment are hard to work with.

P. Franks:

- Theme idea: To stop AIDS is to build community.

J. Stryker:

- Introduction. Look at what we can expect in the next ten years. Particular communities. Why is AIDS special? Stigmas of discrimination, transmission. Rod Wallace in Synergism of Plagues. How AIDS parallels what's going on among the urban poor. Communities becoming synergies of plagues. Intro --

set up some of this tension which will occur throughout the rest of the report.

P. Franks:

- Voices. Take the voices and use as chapter prologues. Voices of those with HIV.

T. Brandt:

- One reason why the "Nation at Risk" had impact that it did was that it was universal. Looked at the nation at risk. We ought to focus on persons self interest rather than charity. A nation at risk engages one's self interest.

M. Byrnes:

- I've always liked Act Up's poster: "We're all living with AIDS" Community. I'm not pushing this theme but something that suggests something similar.

J. Stryker:

- Referring to a discussion that I had with Molly Coye a week ago, I was thinking of some of the rich testimony we have had. On funding we had a quote from the Dallas hearing"...AIDS has shown that health care in the United States is rationed..." For the Public Health system part of the report I am sure that there are quotes that can help define what the section should address.

R. Fullilove:

- The "Nation at Risk" didn't tell anyone anything new, but it gave those with the ideas something to latch on to. It created a brief window period that allowed those who had the initiative with the opportunity to take the issues in the report to the floor of the legislature and other policy making bodies. I suspect that disparate forces that need a focus. There is a need for the Commission to forge communities in a number of different ways. Need to find common ground from which to speak in one voice. Way of organizing the information to forge a new community. What do you want the audience to do, not just what you want them to know. Can think of an objective of what we want the report to say.

General Discussion:

- There are certainly plenty of good quotes in the transcripts from the hearings. The staff will take on the task of trying to find quotes suited to the different sections of the reports and distribute them to the consultants.

Recommendations

M. Coye:

- Where is our list of the recommendations we're writing from? There is a wide range of what you can say. Is there any sense of what the recommendations are going to be? If we are saying

who should be doing this. Where on the spectrum does the community come in. What is to come out. If I said: State responsibility to access care -- I think that would engender controversy. Get more guidelines on those issues.

M. Byrnes:

- With the Johns Hopkins group, have them present a number of recommendations and then present them to Commission. Commission will then give feedback and the bulk of the report will be written to the ones that the Commissioners choose. Research part of the report also has a goal, with Jeff having the opportunity to present the information in March. Not yet done with the structure of the public health system and prevention pieces.

D. Rogers:

- Focus on outcome. Fairly broad brushed so people don't nitpick.

<u>What does the Commission Want?</u>

M. Coye:

- Is it okay then if new ideas come on the table in April? Because only through hearing the Commission can we decide what we want. County/local.. Quality assurance is important here. What does the Commission want to say? Public/private?

D. Rogers:

- I would be very happy to have you write down what you think should happen and then allow Commission to comment on that. If you try to guess what should or shouldn't be said in reference to the Commissioners, then you will get bogged down. Write what you feel. Go to it.

  I also think the more the recommendations are outcome oriented and not too detailed in process the better.

P. Franks:

- By what extent are we bound by what the Commission wants? To what extent should consultants go outside the testimony, etc.? Talking to their colleagues, politicians, community. To what extent can we call these people together?

M. Byrnes:

- Feel free to contact outside experts, and call the office to help you identify information in the hearing materials. Will help you identify things to let people know that the Commission heard their specific pleas.

K. Porter:

- There is a need for references, and the acknowledgement that we know that other people are talking about an issue and

engage that issue in discussion. In the office so far, talking is best way to get input. Want to get ideas.

Post Lunch Discussion

M. Byrnes:

- My sense is that we need to finalize the outline and understand the role of each of the contributors.

P. Franks:

- Three things we need answers for: 1)Content -- audience, purpose, goal, themes and issues. 2)Process -- who takes the lead role of Commission and staff writers, etc. and 3) timeline.

Timeline

March 1:

- Have an abstract, outline, list of recommendations, whatever, for the Commissioners hearing on March 12-13 in Chicago. The Commissioners need "something" that shows quite clearly what you want to do and short whether it's outline or written. Just 2-4 page outline/abstract. Commissioners will have some time set aside to discuss the abstracts.

- It will be Karen Porter's job to contact the consultants to let them know about the discussion on the report.

April 15:

- Draft manuscript.

April 22-23:

- Commission Business meeting on the final report in Washington, DC that all consultants will be asked to participate in.

April 24:

- Consultants will meet together to discuss drafts and Commission input.

June 5-7 Hearing on Prevention:

- The June meeting is to discuss overall report and specifically look at the Prevention chapter. Presenting the information on prevention strategically in the form of a public discussion to get the Commissioners to discuss recommendations and ideas in the Prevention chapter.

July 15:

- Final manuscript due. This will allow for the inclusion of any more up to date information presented at the International Conference in June. Entire month is devoted to final report.

August 1:

- Final sign-off.

August 3:

- Final draft to the printer.

Final Presentation in September:

- Given that August is a rather "dead" time in Washington, DC, it was recommended that we present the final report at a press conference in September after Labor Day.

Outline

M. Coye:

- I have a suggestion on the outline. I thought that the response to the federal government piece is a good and important part that shouldn't be jettisoned. The rough outline lacks role of feds piece. Response of the federal government could go before Chapter 3. All of this is background to who is currently doing things and who should be doing things and how it should be paid for (Revised outline included 2/14).

M. Byrnes:

- It does seem to me that some of these thoughts belong inside the chapter rather than as a distinct part. We can pull parts out of other parts of the report to emphasize them. Talk about specifics in chapters but also have brief section on the public health system and relationships like PH/private sector.

General Discussion:

- The Hopkins group is looking specifically at financing of care. Issues such as financing prevention efforts should be raised in Prevention chapter. These parts may be pulled out a later time and be incorporated in the financing chapter.

- Feel free to contact each other to get feedback on abstracts. Commission will be able to give feedback in the form of global impressions rather than specific comments.

- The Commission staff (specifically Karen Porter) will serve as the liaison for the consultants and the Commissioners

D. Rogers:

- You may be feeling too responsible for the final product. I want you to feel horribly invested in what is in your part of the report but we (staff) are responsible for the final report.

Last Chapter

K. Porter:

- Discussion of the last chapter. Part that you are plugged into Bob, the social context of the epidemic. For me the "what other issues should be discussed" equals the social context and should include a discussion of poverty and

individual v. community and "can any of this work?" Need a reality check.

- Recommendations are not without context, constantly reminds you of the context.

D. Rogers:
- Would permit epilogue -- could be the poetry piece which could say we recognize all these things. Chapter which says we know what this world is all about. Put it in the framework. End piece which incorporates all the malfunctions. We remember the issues -- race, etc.

K. Porter:
- We have to keep these things in mind. Acknowledgement that we are aware of all of these issues

R. Fullilove:
- The way I thought about is, that in a perfect world, everything would be founded on this document. Rather than a competing set of priorities, in the end you have the community. Much of the metaphors used to date have been apocalyptic. Have a slightly utopian view instead. Put it in the framework of "if you do this in terms of AIDS, you can make strides in other areas. Nice way to get people to buy into setting up coalitions.

P. Franks:
- Title -- How to deal with HIV in the context of other social problems. You're making a dent; taking a bite.

K. Porter:
- One thing we should talk about is housing...point to directions where society has not been active.

D. Rogers:
- People begin caring and then a lot of things will fall into place

<u>Length of report</u>

J. Stryker:
- Need to talk seriously about the length of the report. Don't want to get appendicitis, where is the information going to be?

K. Porter:
- Look at IOM "Confronting AIDS" report. The language there is what we want to use. Not in the sense of passion, but the level of language they use -- not too over educated or under educated.

J. Stryker:

- Confronting AIDS is 380 pages. I'm asking how many pages.

D. Rogers:

- I am holding up this example, "Illusions of Immortality", a report on Adolescent AIDS from New York, as a model report. Guts of the report is in 6 double spaced pages. Love to see 10 pages for each chapter. Much harder to write less rather than more, but it has so much more clout. But also has to show what has gone on before the final document (all of the hearings and site visits). That's where the final chapter comes in. When I read a science article I read the conclusions first and then work backwards from there.

<u>AIDS in the International Context</u>

T. Brandt:

- Are we going to say anything about AIDS in the international context.

M. Byrnes:

- Maybe in the introduction and the epilogue.

R. Fullilove:

- Where are we going? Reference to Africa about what may happen context of us in 25 years if we don't do something about this problem.