
Foundations, Nonprofits, and HIV/AIDS in the United States

New Histories of an Epidemic

HIV/AIDS History Collaboratory Meeting Report
Rockefeller Archive Center
Sleepy Hollow, New York
June 13-15, 2017

by Dan Royles

Background	3
Introduction	4
Discussion	5
Political Economy	5
Knowledge Production	6
Actors and Agency	7
Nature of Archives.....	8
Outcomes	10
Lessons.....	10
Meeting as Model.....	10
Next Steps	11
Conclusion	13
Appendix A	14
<i>Meeting Agenda and List of Participants</i>	14
Agenda.....	14
List of Participants	16
Appendix B	18
<i>Archives with AIDS-Related Collections</i>	18
Appendix C	21
<i>New AIDS Histories Conference Collections Report</i>	21

Background

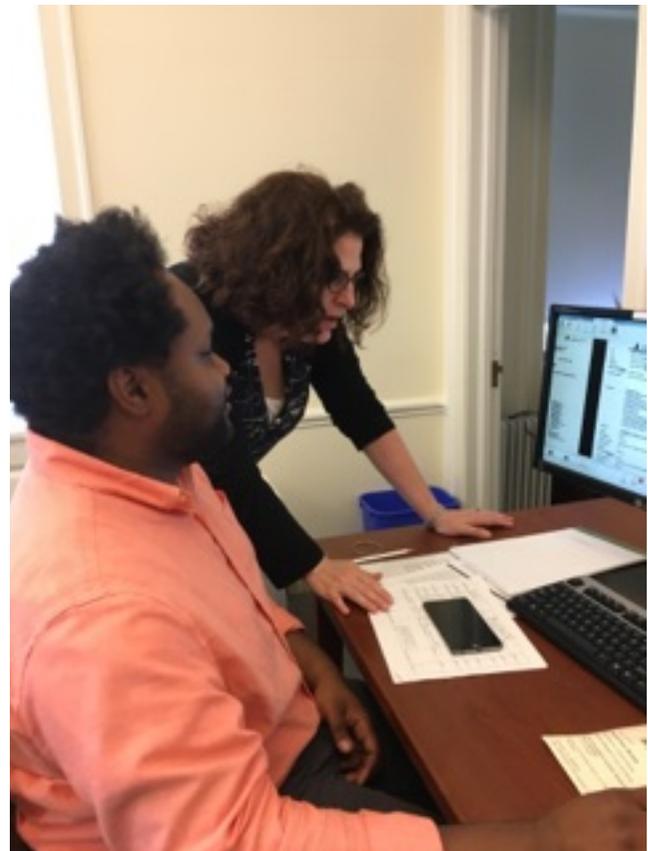
From June 13 to June 15, 2017, the Rockefeller Archive Center (RAC) convened a meeting of scholars, grant makers, and AIDS activists to discuss new directions for the histories of HIV/AIDS and the ways that a better understanding of past philanthropic responses to the epidemic might inform approaches to new and emerging crises.

The history of HIV/AIDS is an emerging field, and little has been written on the role of organized philanthropy in shaping responses to the epidemic. Philanthropic support for AIDS programs in the United States was particularly critical in the early years of the epidemic, when similar public funding was sorely lacking. The Rockefeller Archive Center, which houses collections from over forty private foundations and nonprofit organizations, offers unique insight into this history. The Center's collections illuminate the rationale for such investments; the collaborations, networks, and partnerships that shaped HIV/AIDS interventions; and how AIDS programs in the United States took shape within the context of responses to the epidemic around the globe.

Participants included historians of the epidemic, grant makers who funded the fight against HIV/AIDS during the 1980s and 1990s, and AIDS activists; several participants also bridge the worlds of academia, philanthropy, and activism. Researchers and archivists from the Center also took part in the meeting. Participants

heard from one another about how the history of HIV/AIDS in the United States has taken shape, and how the field may continue to evolve. As one participant commented, "interdisciplinary research has become common in the modern academy, but it is too rare for groupings of academics, each with their own intellectual agendas, to meet with multiple historical actors and field experts." The same participant concluded: "the results were both generative and combusive."

The following report briefly conveys the highlights and outcomes of these discussions, along with an overview of the group's next steps.



Jennie Brier (University of Illinois-Chicago, Astraea Foundation) and Kevin Moseby (Drexel University) comb through archived grant files

Introduction

In the decade after doctors reported the first cases of AIDS in 1981, little federal support for AIDS research, treatment, and prevention of the new disease existed. During the early years of the epidemic, which in the United States killed disproportionate numbers of gay men, drug users, people of color, and the poor, American political leaders largely failed to mount a meaningful response to the new disease. However, the philanthropic sector helped to fill the void left by political leaders' failure to address a devastating public health crisis. For example, one participant points out that the state-level AIDS service organizations she studies was able “to establish themselves and survive, and then go after other grants and other sources of funding” thanks to an initial grant of over \$300,000 from the Robert Wood Johnson Foundation. Along with RWJF, the Ford, Rockefeller, and MacArthur Foundations funded AIDS prevention and education programs in the United States, while the Aaron Diamond Foundation supported medical research on the new disease. Beginning in 1987, the affinity group Funders Concerned about AIDS brought together diverse funders to galvanize further grant making efforts to combat the epidemic.

The philanthropic sector remained crucial to the fight against HIV/AIDS even after significant federal AIDS funds came online. Although the Ryan White CARE Act, passed in 1991, allocated [hundreds of millions \(and later billions\) of federal dollars](#) for a

domestic AIDS response, public resources in the fight against AIDS have lagged far behind need. The introduction of a [National HIV/AIDS Strategy](#) and passage of the Affordable Care Act, both in 2010, represented significant strides toward addressing the disproportionate impact of the disease on vulnerable populations, and particularly on communities of color and the poor. However, the results of the 2016 election threaten this progress, with possible future cuts to the Ryan White program, the Centers for Disease Control, and the National Institutes of Health, along with the proposed repeal of the Affordable Care Act.

New and re-emerging epidemics such as Zika and Ebola also pose threats to global health. These epidemics are driven in part by climate change, on which federal action is unlikely for the foreseeable future. Given the current political climate of fiscal austerity and skepticism of scientific evidence, philanthropic funders will likely once again have to make up for the shortfall in federal funding for basic medical research and public health programs.

Discussion

The bulk of the meeting comprised discussions among participants as well as work in the Center's archival collections. Participants discussed both the state of the field of critical HIV/AIDS scholarship and future directions for scholarship. A handful of key themes emerged from these discussions: political economy, knowledge production, actors and agency, and the nature and function of archives.

Political Economy

A significant body of public health and social scientific research has connected the HIV/AIDS epidemic in the United States to changes in the nation's political economy. Deindustrialization and the "urban crisis" of the 1960s and 1970s provided the context for the rapid spread of HIV; due to the virus' latency period, many of those infected during the 1970s did not experience the symptoms that would lead to an AIDS diagnosis until the 1980s. While many commentators rightly point out that the retrenchment of the welfare state under Ronald Reagan's presidency forestalled an effective response to AIDS, historians should also consider the epidemic in the longer history of white flight from cities, planned urban shrinkage, and backlash against the rights revolutions of the 1960s and 70s.

At the same time, the role of Ronald Reagan and the New Right in worsening the epidemic can hardly be understated. Thanks to the administration's zeal for federal cost-cutting, sexual moralism, and

attacks on welfare, little federal support for AIDS research, treatment, and prevention existed during the first decade of the epidemic. Philanthropies helped to fill this funding gap by supporting medical research, HIV/AIDS education programs, and efforts to reduce stigma surrounding the new disease. As a result, they played an important role in shaping responses to AIDS, both in the United States and around the globe.

The grantmakers in attendance offered behind-the-scenes perspective on this story. They cautioned that some in the philanthropic world were also reluctant to fund the fight against what was widely viewed as a "gay disease." However, the deaths of staff members at these foundations, and especially that of highly respected Ford staff members, drove home the severity of the epidemic to the leadership and program officers, who then moved to fund the fight against AIDS. One participant also stressed the importance of personal networks in disseminating knowledge about HIV/AIDS programs and identifying opportunities for grantmakers. However, the same participant cautioned that the key role of networking in HIV/AIDS funding may not be captured in archival records.

Structural and cultural factors also shaped early HIV/AIDS funding. Foundations and corporate grantmakers were initially loath to fund disease-specific programs. However, program officers at Ford incorporated the epidemic into the foundation's mission by linking the fight

against AIDS in the Global South to their interest in promoting women's health.¹ According to one participant, a former Ford program officer, lessons learned from the fight against AIDS abroad later informed the foundation's domestic work on the epidemic.

Participants also made clear that that different types of funders were able to respond to the epidemic in different ways. For example, large foundations such as Ford could afford to take risks and offer funding over the long term, in order to support innovative AIDS programs. On the other hand, private funders such as the Howard Gilman Foundation ran their own programs, as opposed to making grants, and thus could respond flexibly to the new disease. However, the nature of early AIDS funding may hinder historians' efforts at recovery, since anonymous individual donors were responsible for a significant share of AIDS funding at the outset of the epidemic. Scholars in the meeting were largely unaware of the diversity of funders, and of the ramifications for their own research.

During the discussion, participants also took a critical approach to the role of philanthropy in the fight against AIDS, running primarily along two lines of analysis. On the one hand, participants proposed that philanthropies, along with the grassroots response from affected communities, may have inadvertently

bolstered policymakers' efforts to gut the welfare state by suggesting that a response from the private sector was possible. On the other hand, scholars asked whether there is a tension between the wealth of foundations and the goal of ending an epidemic that is driven by inequality. Put another way, if capitalism is at the root of the AIDS epidemic, can the spoils of capitalism be mobilized to end it?

Knowledge Production

Turning to key concerns in both grant files and the historiography of the epidemic more broadly, participants discussed the role of knowledge production in the fight against AIDS. The field of knowledge about HIV and AIDS has been in a state of constant flux over the course of the epidemic. With this in mind, historians must uncover the diffusion of information about the disease through networks of scientists, activists, and grant makers. But how can scholars determine who knew what, and when?

In the same vein, scholars should pay attention to the ways that knowledge was mobilized in grant files and foundation reports on HIV/AIDS. What forms of knowledge did activists and advocates draw on in making the case for foundation support? Who did grant officers and report authors cite as they crafted their own arguments? Which voices were included in these citation networks, and which were

¹ Jennifer Brier, "AIDS, Reproductive Rights, and Economic Empowerment: The Ford Foundation's Response to AIDS in the Global South, 1987-1995," in *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (Chapel Hill: University of North Carolina, 2009), 122-55.

excluded? What does this tell us about the worldview of foundation staff, and how did that worldview in turn affect the landscape of AIDS funding?

Participants also discussed the role of foundations in producing knowledge about HIV/AIDS. Due to federal restrictions on policy advocacy by foundations, boards and executives have been wary of appearing to advocate specific policy responses to the epidemic. In this context, foundations often chose instead to support research on the social, political, and economic dimensions of the epidemic, which could then be used by policy advocates. However, at least one participant argued that foundation boards should have been bolder in pressing for a robust governmental response to the epidemic. Another participant with extensive grant making experience commented that foundations can afford failure and thus need to take such risks.

Actors and Agency

Participants also discussed the variety of actors—both institutional and individual—that make up the foundation world, as well as the wider world of AIDS activism and advocacy.

Broadly speaking, philanthropies share an interest in promoting the social good. This ethos shapes the way that program officers understand the nature of their work. One participant, a former program officer with the Ford Foundation, offered that the foundation's values served as an ultimate guide in deciding which programs to fund. In this way, professional identity and

institutional mission together shaped funding decisions.

At the same time, individual actors enjoyed significant leeway in deciding which programs to fund. In some cases, as with the Aaron and Irene Diamond Foundations, the donor's interests in large part determined funding priorities. In other cases, a program officer taking over a new funding area might "make it their own" by funding new programs while ending some existing relationships. For grantees, this could be profoundly disruptive and threaten their viability. One participant, and activist whose organization had been funded by the Ford Foundation during the 1990s, shared such an experience. She had enjoyed a warm relationship with one program officer, but not with her successor. Research in the Center's collections additionally uncovered a memo, written by an outside consultant, recommending that the participant's organization be defunded. Her experience speaks to the challenges posed by the meeting's research model (see below).

Relationships between grantmakers and grantees also help determine who gets funded in the first place. Grantees with connections to the philanthropic world are much more likely to be aware of foundations as potential sources of funding, and have an easier time putting together proposals. This arises in part from foundations' commitment to support grantees through the long process of social change, which narrows funding horizons. Programs that lack connections to the

rarefied world of philanthropy find themselves at a distinct disadvantage, as the grantmaking process inadvertently reproduces social inequalities. The ramifications of this pattern for the response to HIV/AIDS, an epidemic that has been driven by social inequalities, could be profound.

Nature of Archives

Discussions also engaged the nature of archives, from both practical and theoretical perspectives. About half of the participants had little to no experience doing archival research. For them, the day spent working in the Center's collections was a new experience.

Practitioners expressed concern about what might be left out of foundation records, particularly the informal communication within foundations and between grantmakers and grantees that is not captured in the more "official" record that grant files comprise. Oral history, a method with which several scholars in the room had significant experience, can help fill these gaps in the archival record. Although oral history has been closely allied with the "new social history," which focuses on telling stories "from the bottom up," its origins lie in the work of Allan Nevins, who became concerned while working a biography of Grover Cleveland that the shift to standardized forms of record-keeping and advent of the telephone had sapped the archival record of meaning.² Hence, oral

history was originated to solve precisely the problem of archival silences that practitioners at the meeting identified.

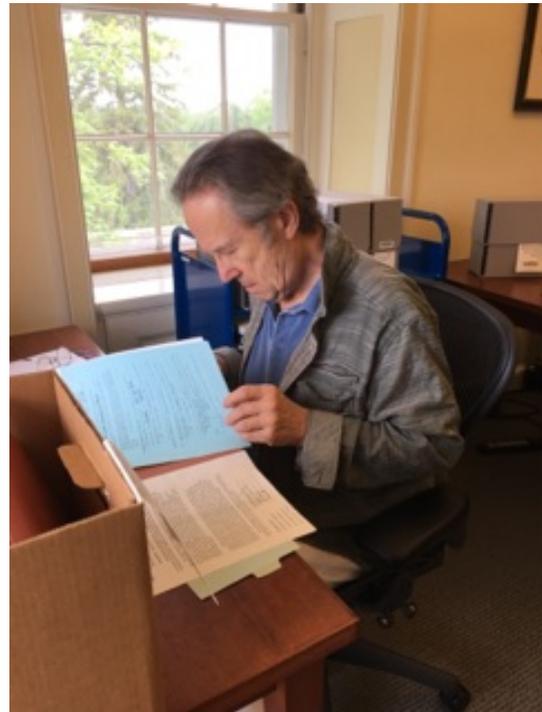
Technological changes also pose particular problems for historians of HIV/AIDS. The advent of the recognized epidemic in the 1980s coincided with rapid technological change, including the widespread use of word processors, electronic records keeping, and email. Decaying digital storage media, the ephemerality of web-based sources, and ever-changing file formats and operating systems all pose significant digital archiving challenges, and the solutions to these problems will significantly shape future writing on the history of HIV/AIDS. With this reality in mind, foundations should also be proactive in planning for the long-term preservation of digital records.

Participants also shared a concern with how to "read between the lines" in grant files. One pointed out that "every grant is a great success," meaning that program officers tend to describe programs in positive terms, even when they are problematic. Another remarked that he "was reminded how foundations and their language can be opaque and bewildering." Historians thus need to understand the terms in which foundation staff would be likely to describe such programs. Scholars might also closely read a program's budget for signs of trouble, but may not be trained in such a task. Hence, ongoing efforts to promote the

² Alistair Thomson, "Four Paradigm Transformations in Oral History," *The Oral History Review* 34, no. 1 (January 1, 2007): 49–70.

history of philanthropy might focus on teaching scholars to critically parse these parts of grant files.

Another solution to this problem is to have scholars and practitioners examine grant files together. Several participants approached the research day in this fashion, with scholars and practitioners pairing up to examine records together. Activists and grantmakers helped scholars to interpret documents in what proved to be an especially fruitful exercise. Many participants felt strongly that this collaborative research method would be useful in examining other histories of the recent past. One participant remarked, “While [another participant] and I went through the records of the Ford Foundation together... we narrated different contexts to one another to understand the grant. She was able to tell me about the various personalities who were mentioned or cited, I was able to describe the context of what the foundation had done in the previous decade. We should have recorded it!” She continued, “The temporary collaboration, sitting at the microfiche machine, sparked a set of questions that I would not have come to on my own.” Indeed, future efforts by the group might include oral histories *in situ*, in which a scholar records their conversation with a grantee or program officer while digging through their files. However, it is worth noting that archives are not generally set up for this kind of work, which might necessitate rethinking everything from archival policies to the spatial arrangement of the reading room.



Vincent McGee (Aaron Diamond Foundation, Irene Diamond Fund) in the Rockefeller Archive Center reading room



Tom Rosenbaum (Rockefeller Archive Center) and George Aumoithe (Columbia University) share a hallway chat

Outcomes

Lessons

The meeting also revealed scholars' lack of familiarity with the world of philanthropies and nonprofits, and vice versa. While one historian in attendance is also an experienced grantmaker, the other scholars in the room were unfamiliar with how the process of philanthropic grantmaking works. Moreover, scholars who are unfamiliar with the world of grantmaking may not know what they do not know. These gaps in knowledge may be filled by conversations with grantmakers at similar meetings such as this one. However, a set of resources for scholars interested in using foundation grant files in their research might also be developed to foster the use of collections like those held at the Rockefeller Archive Center.

Meeting as Model

This meeting may serve as a useful model for collaboration among scholars, archivists, and practitioners. Today's most pressing problems are rooted in historical context. Philanthropies have also played a significant role in shaping that history, with foundation staff also playing roles in the state and social movement sectors as well. Scholars stand to learn a significant amount about that history from conversations with grantmakers, and philanthropies in turn can well learn from scholars about past programs that have succeeded or fallen short.

Participants found the research portion of the meeting to be especially fruitful. One scholar in attendance pointed out that it is "every historian's dream to work with the people who actually made the decisions." Another envisioned the experience as a new model of "cluster research, that enables archivists, historians, practitioners and grantmakers to together on a set of documents." He added that this process also involves an interdisciplinary exchange among scholars and practitioners, who might each be unfamiliar with the language and conceptual frameworks that undergird the other's work.

However, the model is not without potential pitfalls. While working in the archives, grantmakers might run across documentary materials that contradict their personal memories, which can be distressing. Participants might make other troubling discoveries, as happened when one participant discovered memos recommending that her own organization be defunded. She found that being paired with a scholar helped her to process such emotionally challenging material. In her words, "a buddy approach was necessary for this kind of work." However, the same participant, drawing on the work of anti-racist advocate Bryan Stevenson, also stressed the importance of "getting uncomfortable"—and of making others uncomfortable as well—as a step toward significant change.³

³ Bryan Stevenson, *Just Mercy: A Story of Justice and Redemption* (New York: Spiegel & Grau, 2014).

Next Steps

Since the June 2017 meeting at the Rockefeller Archive Center, the group has continued to meet by phone. The group plans to propose a session on the history of philanthropic responses to HIV/AIDS for the 2018 International AIDS Conference in Amsterdam, and will seek funding for future meetings to elaborate the collaborative research model described above. Future meetings will also include scholars with an interest in the history of HIV/AIDS outside of the United States, as well as researchers from the world of HIV science and medicine. Their participation will expand the scope of the group's study, and thus broaden the reach of its work.

The group envisions several key products of its collaboration, spanning the study of both HIV/AIDS history and the history of philanthropy, as well as the practice of philanthropy in the present and future. One such outcome is a collection of case studies of private funder support for HIV/AIDS programs, particularly in the 1980s and 1990s. This group of funders includes major philanthropies such as Ford and Rockefeller, smaller limited-term funders such as the Paul Rapoport Foundation, and other private or semi-private funders such as the United States Conference of Mayors. Research for these case studies will in part be conducted through conventional archival methods, but such an effort offers the opportunity to employ collaborative, oral, and digital methods as well.

Collaborative research among scholars, philanthropic practitioners, and activists will not only to produce new historical knowledge about the history of HIV/AIDS, but proffer a new model for the production of historical knowledge. As part of this work, the group also plans to conduct oral histories *in situ*, with an initial focus on collections held at the Rockefeller Archive Center. This approach offers a new way of thinking about authority in the practice of history, in addition to reimagining the archive as a space for the *production* of historical records. This work will altogether show how the nature of historical research changes when it is expanded to include participants from multiple sectors, and will be broadly useful for the study of the recent past.

Meanwhile, the group will use digital methods to answer some of the key questions raised in discussions at the June 2017 meeting. For example, participants will use network analysis to trace the connections among philanthropic practitioners, grant recipients, academics, and policy makers. This will in turn allow the group to draw larger conclusions about the ways that HIV/AIDS knowledge was produced and disseminated with philanthropic support, and to understand the role of social and professional connections in shaping the landscape of HIV/AIDS funding. In a similar vein, large-scale text analysis of grant files will uncover the ways that the language used to frame HIV/AIDS programs changed over time, as well as the sources of knowledge that

program officers and grant recipients drew from in shaping that language.

This collaborative model will also help to address the gaps in knowledge that exist among sectors, which can hinder the ability of historians to critically engage with grant files and foundation records. Here the group envisions a brief primer on the world on philanthropic grant making to aid scholars—regardless of subfield—in mining these types of archival sources in their own research. The guide would in turn encourage the use of collections such as those held at the Rockefeller Archive Center.

Through this research, the group will also produce a report for contemporary philanthropies about lessons to be learned from the history of HIV/AIDS grant making. At present, new and emerging crises threaten human life on a global scale, philanthropy is being remade by an infusion of new wealth from Silicon Valley, and the future of federal funding for the fight against HIV/AIDS in the United States and abroad appears uncertain at best. This moment is one of both tremendous peril and opportunity, and the group aims to show that lessons drawn from the study of past grant making can help to make future philanthropy more effective and equitable.



George Aumoithe (Columbia University) in the Rockefeller Archive Center reading room; Dázon Dixon Diallo (Sisterlove, Inc.) and Jennie Brier (University of Illinois-Chicago, Astraea Foundation) working in background

Conclusion

The philanthropic “third sector” has played an important role in supporting the fight against HIV/AIDS, particularly in the early years of the epidemic when public funding for such efforts was sorely lacking.

However, little of this story appears in the emerging historical scholarship of the epidemic. This group proposes a research agenda for the history of HIV/AIDS grant making that will span disciplinary approaches and include actors from various sectors of the fight against the disease. In this way, the group aims to connect the results of this work not only to historians, but to the international community of AIDS researchers, advocates, and funders as well.



Collaboratory members enjoying lunch on the Rockefeller Archive Center patio

Appendix A

Meeting Agenda and List of Participants

Foundations, Non-Profits, and HIV/AIDS in the United States:
New Histories of an Epidemic
Meeting/Workshop
Rockefeller Archive Center, Sleepy Hollow, New York
June 13 – 15, 2017

Agenda

Tuesday, June 13, 2012

9:00-10:30 AM

- Welcome
- Purpose of Meeting and Agenda
- Introductions

10:30-10:45 AM Mid-Morning Break

10:45 AM-12:15 PM

- Discussion: What kinds of histories of HIV/AIDS have—or have not—been written?

12:15-1:15 PM Lunch

1:15-3:00 PM

- Discussion: What have been grantmakers' and activists' experiences with HIV/AIDS? How are these experiences reflected (or not) in scholarship about the epidemic? In popular memory? In contemporary prevention programs? How do we define "AIDS activism"?

3:00-3:15 PM Mid-Afternoon Break

3:15-5:00 PM

- Discussion: What are the openings for new HIV/AIDS histories? How do the perspectives of HIV/AIDS scholars, grantmakers, and activists fit together? What key questions emerged from morning discussion and afternoon roundtable that we can take into the archive? What do we want to learn from the RAC collections?

5:30-8:00 PM Reception and Dinner—Tramonto (transportation provided)

Wednesday, June 14

9:00 -10:00 AM

- Presentation (RAC Archivists): RAC policies
- Discussion (Grantmakers/RAC Historians): What kind of materials can we expect to find in the collections? What kind of material can be unexpectedly informative? What do we need to know about how grantmaking works?

10:15 AM-12:30 PM

- Archival Research

12:30-1:30 PM Lunch with RAC Archivists

1:30-3:45 PM

- Continue Archival Research

3:45-4:00 PM Mid-Afternoon Break

4:00-5:00 PM

- Discussion: How do archival materials address questions raised on Tuesday? What new questions arose during our research?

Wednesday Night: option of informal dinner at hotel or in Tarrytown

Thursday, June 15

9:00-10:30 AM

- Discussion: What from the archival materials seems most promising? Which collections warrant further investigation? What new questions arose during our research?

10:30-10:45 AM Mid-Morning Break

10:45 AM-12:15 PM

- Discussion: What product(s) (e.g. an edited collection, white paper, teaching resources) should come out of the meeting?

12:15-1:15 PM Lunch (option to continue morning discussion)

1:15-3:00 PM

- Discussion: What are the next steps needed toward the product(s) decided on in the morning discussion? In what capacity will individual participants be involved?

List of Participants

Invited Participants

George Aumoithe, PhD Student, History, Center for the Study of Social Difference, Columbia University, New York, NY.

*Katie Batza, Assistant Professor, International & Interdisciplinary Studies-Women, Gender & Sexuality Studies, University of Kansas, Lawrence, KS.

Jennie Brier, Associate Professor, Women and Gender Studies, Department of History, University of Illinois-Chicago, IL.

Stuart Burden, Vice President, Corporate Responsibility, Silicon Valley Community Foundation, Mountain View, CA

Elizabeth (Beth) Clement, Associate Professor, Department of History and Affiliated Faculty, Department of Gender Studies, University of Utah, Salt Lake City, UT.

Dázon Dixon Diallo, Founder and president, SisterLove, Inc., Atlanta, GA.

*Mark Harrington, Co-Founder and Executive Director, Treatment Action Group, New York, NY

Kwame Holmes, Assistant Professor, Department of Ethnic Studies, University of Colorado, Boulder, CO.

Vincent McGee, Senior Advisor, The Atlantic Philanthropies, New York, NY.

Kevin M. Moseby, Assistant Teaching Professor of Sociology, Department of Sociology, Drexel University, Philadelphia, PA

Marjorie Muecke, Assistant Dean, Global Health Affairs, and Associate Director, WHO Collaborating Center for Nursing and Midwifery Leadership, School of Nursing, University of Pennsylvania, PA.

Dan Royles, Assistant Professor, Department of History, Florida International University, Miami, FL. (meeting co-organizer)

Michael Seltzer, Distinguished Lecturer, Marxe School of Public and International Affairs, Baruch College, The City University of New York, New York, NY.

Rockefeller Archive Center Participants

Bethany Antos, Archivist

Michele Beckerman, Assistant Director, Head of Reference

Monica Blank, Archivist

Bob Clark, Director of Archives

Meg Hogan, Lead Archivist, Appraisals and Digital Services

Jack Meyers, President

Brent Phillips, Audiovisual Archivist

Mary Ann Quinn, Archivist

Tom Rosenbaum, Archivist

Patricia Rosenfield, Senior Fellow (meeting co-organizer)

Barb Shubinski, Assistant Director, Research and Education

James Allen Smith, Vice President and Director of Research and Education

Rachel Wimpee, Historian and Project Director

Marissa Vassari, Assistant Archivist and Educator

*Unable to participate at last minute but continuing as part of the group.

Appendix B

Archives with AIDS-Related Collections

ACT UP Oral History Project

African American AIDS Activism Oral History Project

Brown University

- ACT UP Rhode Island Records

Emory University

- David Lowe Papers
- Ed Stansell Papers
- National Association of Black and White Men Together Records

George Bush Presidential Library

- Records on HIV/AIDS Policy

Human Sexuality Collection, Cornell University Library

- ACT UP Ithaca Records
- David Petersen Papers
- John W. Hollister Papers
- PWA Health Group Records
- Robert Garcia Papers
- Robert Roth Papers

New York Public Library

- Aaron Diamond Foundation Records
- ACT UP New York Records
- AIDS Activist Videotape Collection
- AIDS and Adolescents Network of New York Records
- AIDS Theater Project Records
- Aldyn McKean Papers
- Arthur Ashe Archive
- Bradley Ball Papers

- Craig Harris Papers
- David Dunlap Papers
- Gay Men of African Descent Records
- Gay Men's Health Crisis Records
- Gran Fury Collection
- James Turcotte Papers
- Joseph Beam Papers
- Joseph Sonnabend Papers
- Lawrence Mass Papers
- Mark Lowe Fisher Papers
- Other Countries Records
- Robert Penn Papers
- People with AIDS Coalition Records
- Ron Simmons Papers
- Testing the Limits Records
- Tony Davis ACT UP Records
- Vito Russo Papers

GLBT Historical Society (San Francisco)

- Black and White Men Together San Francisco Bay Area Records
- National Task Force on AIDS Prevention Records

National Library of Medicine

- National Commission on AIDS Records

ONE Gay and Lesbian National Archives

- AIDS History Project Collection LA
- Alan Cantwell Papers

John J. Wilcox Archive at the William Way Community Center (Philadelphia)

- Kiyoshi Kuromiya Papers

San Francisco Public Library

- AIDS Ward 5B/5A Archives
- Gary Fisher Papers

- John Iverson ACT UP/East Bay Collection
- David Lourea Papers
- Milton Marks Papers
- People vs. Owen Bathhouse Closure Litigation Records
- Randy Shilts Papers

Smithsonian

- John-Manuel Andriote Victory Deferred Collection

Sophia Smith Collection

- Dázon Dixon Diallo Papers
- SisterLove Records

Temple University

- AIDS Library Records
- Scott Wilds Papers

University of California, San Francisco

- AIDS Community-Based Organizations Records
- Bay Area HIV Support and Education Services (BAHSES) Records
- Multicultural AIDS Resource Center Records
- National Task Force on AIDS Prevention Records
- San Francisco AIDS Foundation Records
- Nancy Stoller Papers

University of Chicago

- ACT UP Chicago Records

Yale University Library

- AIDS Collection
- Larry Kramer Papers

Appendix C

New AIDS Histories Conference Collections Report

Dan Royles

September 2016

Precis: Philanthropies have played a significant role in the fight against AIDS, both in the United States and around the world. As such, the cohort of historians now engaged in writing the next wave of AIDS histories should take seriously the philanthropic sector's role in the stories they tell. The Rockefeller Archive Center is uniquely positioned to assist in this regard. The Center can introduce scholars to relevant archival collections, help them understand how to use the documents contained therein, and connect them to the grantmakers who shaped the foundations' response to AIDS. This report outlines several key themes that emerge from a survey of the Center's collections, and suggests approaches for a multi-day workshop for AIDS historians.

Thirty-five years ago, doctors first announced what would later become known as AIDS, a disease that has killed 35 million worldwide and almost 700,000 in the United States alone. During the early years of the epidemic—which in the United States killed disproportionate numbers of gay men, drug users, people of color, and the poor—American political leaders largely failed to mount a meaningful response to the new disease.

However, the philanthropic sector helped to fill the void left by political leaders' failure to address a devastating public health crisis. In a time of weak public funding to fight what was widely viewed as a "gay disease," foundations supported medical research, HIV/AIDS education programs, and efforts to reduce stigma

surrounding the new disease. Major philanthropies such as the Rockefeller and Ford Foundations incorporated funding for AIDS programs into their existing vision of global progress, while smaller limited-term funders such as the Aaron Diamond Foundation and the Paul Rapoport Foundation devoted a significant portion of their resources to the fight against AIDS. Meanwhile, affinity groups such as Funders Concerned About AIDS coordinated the fight against AIDS across the philanthropic sector.

Even after significant federal funding for AIDS research, treatment, and prevention became available, foundations maintained an active role in charting the response to AIDS, both at home and abroad. They continued to fund groups such

as the National Association of People with AIDS and the National Minority AIDS Council, while producing reports about the response to AIDS from both philanthropic funders and the federal government. In this way, foundations not only provided material support to the fight against AIDS, but served as a critical voice from civil society in the debate over priorities within that fight.

Thus, philanthropies played an important role in shaping the fight against AIDS in the United States. As historians increasingly seek to chronicle the history of the AIDS epidemic, both in the United States and abroad, the role of the foundations in the fight against the disease will be an area of significant inquiry. How did philanthropies shape AIDS education and prevention efforts? What types of programs did they elect to fund, and why? How did the foundations' funding priorities dictate which programs received support? How did philanthropic funding priorities compare to those in the public sector?

At the same time, foundation grant files represent a unique trove of information about the grassroots AIDS education and prevention efforts that received philanthropic funding, and particularly for those organizations that are now defunct, or for which few archival records exist. Even for historians whose research questions do not directly address the history of philanthropy, grant files provide invaluable information about the history, mission, and activities of AIDS

service organizations, which might otherwise be inaccessible.

The Rockefeller Archive Center is uniquely positioned to aid scholars in the research and writing of the history of the AIDS epidemic. First, the Center's collections include records of the philanthropic response to AIDS that number in the tens—if not hundreds—of thousands of pages. Moreover, these collections can be used to address several key themes in the emerging historiography of HIV/AIDS:

HIV/AIDS and the social determinants of health

Public health scholarship has long recognized that the greater a person's level of social marginality—whether because they are non-white, poor, queer, or for a host of other reasons—the more likely they are to suffer ill health. The same is true in the context of HIV/AIDS: communities of color, gay and bisexual men, transgender women, the homeless, and incarcerated people all experience rates of HIV infection well above the average. Many AIDS service organizations have thus worked to combat the epidemic by simultaneously attacking social ills such as racism, sexism, and homophobia, as well as inequalities in health care and housing. Indeed, the Rockefeller Archive Center's collections reflect this focus on the role of social determinants of health in the AIDS epidemic. Relevant holdings include grant files for the American Civil Liberties Union, AIDS Housing of Washington, and the

National Minority AIDS Council. The office files of Stuart Burden also contain correspondence with the New York Bar Association regarding their interest in addressing HIV/AIDS within the state's criminal justice system. Files distributed across different collections include those documenting the Ford Foundation's *AIDS: The Politics of Inclusion* initiative, led by Marjorie Muecke during the 1990s, which aimed to "change the infrastructure of exclusion" that accelerated the spread of HIV in vulnerable populations around the globe.

Response to HIV/AIDS from communities of color:

As noted above, HIV/AIDS has taken a vastly disproportionate toll on communities of color in the United States, and particularly on African Americans. Historians of AIDS must document not only the social inequities underlying the epidemic within communities of color, but also the ways in which people in those communities mobilized against the disease. Without a full accounting of this history, it becomes all too easy for writing about AIDS in communities of color to fall into racist tropes about the powerlessness, passivity, or ignorance of those most affected. Here too, the Rockefeller Archive Center's collections can help to document the diverse ways in which communities of color mobilized against the spread of HIV/AIDS. Relevant holdings include grant files for the Black Leadership Coalition on AIDS, the Latino Commission on AIDS, the National Minority AIDS Council, and the Balm in

Gilead, which fosters AIDS education in black churches. Additionally, a 2001 report by sociologist Cathy Cohen offers an overview of the Ford Foundation's record of giving to the fight against AIDS in minority communities from 1988 to 2000.

The United States' role in the fight against global AIDS:

For better or for worse, the United States has undoubtedly played a leading role in the fight against AIDS around the world, first as a major funder of the World Health Organization's Global Program on AIDS and through USAID, and later through the President's Emergency Plan for AIDS Relief, begun in 2003. These international efforts could hardly be divorced from domestic American AIDS politics, as historian Jennie Brier has shown in her work on both the Reagan administration's response to AIDS, both at home and abroad, and the feminist politics of the Ford Foundation's giving to AIDS programs in the Global South. Indeed, the Rockefeller Archive Center's collections detail the various ways in which the Rockefeller and Ford Foundations have shaped international and transnational responses to HIV/AIDS around the world. In the realm of official international relations, grant files for the Human Rights Project and the Kaiser Family Foundation document efforts to assess and influence the place of U.S. AIDS policy in the global AIDS pandemic. On the other hand, foundation funding has also supported the work of non-state actors whose work on HIV/AIDS crosses national boundaries.

These include the Companions Program and the US-Mexico Border Health Association, both of which brought AIDS services to the Ciudad Juarez/El Paso border region, and various groups that connected the fight against AIDS in black American to the fight against AIDS in sub-Saharan Africa, including AIDSLink, the Atlanta Area Health Education Center, and the Balm in Gilead, which has worked with black churches in the Caribbean and in Africa, as well as in the United States.

Again, historians of the AIDS epidemic will need to consider the role of the philanthropic sector in shaping responses to the disease. The Rockefeller Archive Center is uniquely equipped to assist in this endeavor. The Center possesses a wealth of archival collections detailing everything from grassroots HIV prevention efforts to federal AIDS policy formulation, along with the intellectual and institutional resources to help the next generation of AIDS historians interpret those holdings.

A workshop for AIDS historians at the Rockefeller Archive Center would help to highlight the above collections, and thus introduce participants to new archival materials. Discussion of the themes that emerge from these holdings will help to set an agenda for future work by historians of the epidemic and connect that work to larger histories of public health, inequality, and activism. At the same time, the Center's staff can help participants interpret the materials at hand. How can historians use the information in grant files to ask and

answer new research questions? How can we assess changes to funding priorities over time? How can we gauge the types of programs that may have been proposed, but which went unfunded? Finally, the Center can help to connect participants to key players in the philanthropic response to AIDS. This will allow participants to ask questions of the funders, and for the funders to share their personal stories of the fight against AIDS. Thus, the Rockefeller Archive Center can leverage its unique material, intellectual, and institutional resources to foster rich, nuanced, and critical histories of HIV/AIDS in the United States and beyond.