Insights and Innovations in Community Mental Health

The Erich Lindemann Memorial Lectures

organized and edited by
The Erich Lindemann Memorial Lecture Committee

hosted by William James College

William James
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Foreward

The Erich Lindemann Memorial Lecture is a forum in which to address issues of community mental health, public health, and social policy. It is also a place to give a hearing to those working in these fields, and to encourage students and workers to pursue this perspective, even in times that do not emphasize the social and humane perspective. It's important that social and community psychiatry continue to be presented and encouraged to an audience increasingly unfamiliar with its origins and with Dr. Lindemann as a person. The lecturers and discussants have presented a wide range of clinical, policy, and historical topics that continue to have much to teach.

Here we make available lectures that were presented since 1988. They are still live issues that have not been solved or become less important. This teaches us the historical lesson that societal needs and problems are an existential part of the ongoing life of people, communities, and society. We adapt ways of coping with them that are more effective and more appropriate to changed circumstances—values, technology, and populations. The inisghts and suggested approaches are still appropriate and inspiring.

Another value of the Lectures is the process of addressing problems that they exemplify: A group agrees on the importance of an issue, seeks out those with experience, enthusiasm, and creativity, and brings them together to share their approaches and open themselves to cross-fertilization. This results in new ideas, approaches, and collaborations. It might be argued that this apparoach, characteristic of social psychiatry and community mental health, is more important for societal benefit than are specific new techniques.

We hope that readers will become interested, excited, and broadly educated.
For a listing of all the Erich Lindemann Memorial Lectures, please visit
www.williamjames.edu/lindemann.

The Erich Lindemann Memorial Lecture Committee presents

THE FIFTEENTH ANNUAL
ERICH LINDEMANN MEMORIAL LECTURE

Community-Focused Health Care: The AIDS Example

Case Conference Participants

Nicolás Parkhurst Caballeira, BSc, CTT, ND: Executive Director, Latino Health Network; Board of Directors, Massachusetts AIDS Discrimination Initiative

Calvin J. Cohen, MD, MS: Research Director, Community Research Initiative of New England; Principal Investigator, International Observational Data Base Project, AmFAR Community-Based Clinical Trial Network; Clinical Instructor, Harvard Medical School

Judith Kurland: Commissioner, Boston Department of Health and Hospitals

Moderator

David G. Satin, MD, LFAPA: Assistant Clinical Professor of Psychiatry, Harvard Medical School; Chairman, Erich Lindemann Memorial Lecture Committee

Friday, April 24, 1992, 2:30 – 5:30 pm

Massachusetts School of Professional Psychology
221 Rivermoor Street, Boston, MA 02132

Introduction by David G. Satin, MD

The topic chosen for this year's Fifteenth Annual Lindemann Memorial Lecture is community-focused healthcare: the AIDS example. AIDS is a public health issue of great current concern, and therefore merits some attention at this lecture. Its influences are increasingly spreading through the social fabric. It's not just one more illness—it's something that affects clinical care, research effort, funding, the determination of social priorities, civil rights, employment, education, and many other aspects of our society, and of the world's society. Seems to me that it's not since the great plagues of the past--tuberculosis, smallpox, typhoid and typhus, cholera, the bubonic plague—that a public health issue has so affected the total body politic, that social priorities and resources as a whole have been debated and reconsidered, and it seemed to me that, with this plague also, the public, the community, has taken the initiative away from government bodies, professions, and academic institutions to deal with something that's so oppressed and affected the community as a whole.

The Fifteenth Annual Erich Lindemann Memorial Lecture addresses the community initiative in responding to public health problems with the AIDS plague as our current example. The format for the lecture will be a presentation by each member of our panel on advocacy, research, and public policy and resource allocation.

Nicolás Parkhurst, Caballeira BSc, CTT, ND

Executive Director, Latino Health Network; Board of Directors, Massachusetts AIDS Discrimination Initiative

Introduction by David G. Satin, M.D.

Let me start with introducing Nicolás Parkhurst Caballeira. Mr. Parkhurst is currently the Executive Director of the Latino Health Network in Boston, and recently the Director of Education and Community Outreach at the Multicultural AIDS Coalition. He has a certification as Doctor of Naturopathy, and has his bachelor's degree from the University of the State of New York, a CTT degree from the Ozark Life Center School of Therapy Technology, an ND degree from the Ayurvedic Institute and Clayton School of Natural Healing, and is in the process of getting his master's degree in public health at the Boston University School of Public Health. He is a member of the Massachusetts Public Health Association, the American Public Health Association, and the International Society for AIDS Education. He has been Assistant Dean for Academic Affairs, in charge of university development, the AIDS Project and Community Relations at the University of Puerto Rico, and was Executive Director of the Puerto Rico Medical Sciences Foundation. I introduce Nicholas Parkhurst to talk about advocacy in the AIDS condition.

Nicolás Parkhurst, Caballeira BSc, CTT, ND

Thank you. Good afternoon. I'd like to thank Dr. Satin and the members of the Lindemann Lecture Committee, and the members of the Lindemann family for the opportunity to be here today. I understand that I am the first Latino professor in this cycle of Lindemann Lectures, and I trust that I will not be the last. I think that it's particularly fitting that the first Latino speak this year when we commemorate 500 years of Pan-American epidemic and demographic collapse. It is estimated that over 94% of the native peoples of this hemisphere died of epidemic disease, epidemic violence, epidemic substance abuse and genocide as a direct consequence of the European invasion that began in 1492, and continues unabated to this day. Three hundred years after the Europeans occupied these lands, less than four million remain of the more than 72 million native inhabitants that they encountered upon their arrival. So as we gatherhere to discuss community-focused health, I want to honor the memory and the valiant resistance of the people of these lands by beginning with a story that will serve as a conceptual reference for my remarks this afternoon.

It's a story of a very wise woman and leader of her people of the land of Borriquien, which you may know by its Spanish colonial name of Puerto Rico. This was a very wise woman, who ruled her own people, and was invited in one occasion to a neighboringnation to help them address a very substantial problem that they were facing. She was invited by the elders, she and attended a meeting of all the people. When she got there, she listened to the people express what the nature of the problem was. And then she proceeded to take a twig of guayaba, or guava, and draw this on the ground, and she then asked them, 'Do you know what this is?', and they looked, and they said, 'It's a very old symbol of our own nation. But we don't know what it means'. And she said, 'If you do not know what it means, then I am of no use to you,' and she left. The elders discussed among themselves. They decided that they would bring her back, invite her back, and that they would tell her that yes, they did know what the symbol meant, to see if she then would expound on their problem, and give them the solution to their problem. She accepted the invitation, came back. Actually the name of this symbol is in Spanish the quincumse. I have a very hard time saying that in English, so if you'll bear with me I will say quincumse throughout my presentation.

The quincumse was still on the ground. She came back and she said, 'Well, do you know what the quincumse means?', and they all said, 'Yes,' and she said, 'Wonderful, since you know what it means, you don't need me here,' and she left. The elders again got together and decided, 'Well, you know, she hasn't helped us at all. We have to find a way to make her speak to us and tell us what to do'. So they came up with this wonderful idea. They invited her back, she accepted the invitation, she came back. The whole people were gathered, she said, 'Do you know what this means?', and after rehearsal, half of the people said, 'Yes' and half of the people said, 'No', and she said, 'Wonderful. Now, you who know, explain it to you who don't know,' And she never came back.

Now, this story, I have heard it repeated from many different cultural backgrounds, so it's probably an archetypal story. I don't think it can be lost on those who attempt to promote community-focused health. The quincumse, or the original mold of life, or as the Incas called it, the Sapa, the original and unique pattern of life, has many different patterns and many different uses. But the main use is to focus the attention of those who use it on their own knowledge, for we can never ever learn that which we do not already know. For native peoples, as for most of us today, when I say 'most' unfortunately there are some who don't, health is more than the

absence of disease. But for native people, native peoples it is also more than that, it's more than the capacity to grow, mature, reproduce and die naturally, it is actually the exercise of that capacity. And when we speak of exercising the capacity, we are talking about power, and you will forgive me, but, yes, I will say the word 'empowerment'.

We are talking about empowerment. Now, to empower means to identify, develop, define, and utilize one's skills, gifts and assets. It is a reflexive verb and it is an intransitive verb, we hear a lot and in fact we see many proposals written these days that mean to empower people, as if empowerment was something you can do to people. You cannot empower people--you can only provide resources and facilitate the opportunities for their own empowerment.

Now according to this native definition of health, the exercise of the capacity to grow, mature, reproduce and die naturally, then those who lack the power to exercise this capacity by definition lack health. It has taken Europeans both in Europe and those occupying these lands approximately 500 years to come to a similar conclusion. Powerlessness is now gaining currency as a broad risk factor for disease. A review of the literature of socioepidemiology, occupational and stress research, social and community psychology, community competence and community organizing gives credence to this postulate. The work of Paulo Freire, which was originally developed for education and literacy, is also gaining adherents now in public health circles, with itís focus on empowerment. Now, with Freire we learn that the context in which health intervention happens is not neutral, because people bring their power or their powerlessness to interactions with health professionals.

Now, while we're used to looking at certain health-related issues, and particularly mental health issues, in the context of powerlessness, and issues such as access to services are usually seen from that perspective these days, we seldom look at disease itself as powerlessness. From the native perspective, biological powerlessness is part of a pattern, a mold of powerlessness, and an effective approach to AIDS is one which breaks the pattern.

Now I think that the use of AIDS to talk about community-focused health is actually quite brilliant, because AIDS makes the connection between powerlessness and disease obvious and inescapable. With other diseases we may have doubts about it, but actually if we define AIDS in the simplest, most basic way we can define it as a lack of power to resist disease. Does anybody really have a disagreement with that basic definition? Now we see in the literature that long-term survivors of AIDS tend to take charge of their lives and their treatment, and they empower themselves and break out of the mold of powerlessness. Communities are no different than individuals. In fact from the native perspective, individuals are microcosmic communities, and communities are but macrocosmic individuals.

For the relatively powerless, there are two potential paths to greater empowerment: the individual and the collective. Let's look for a moment at the quincumse of powerlessness, which is very similar to the north Native Americans talk about the medicine wheel, maybe you're more familiar with that, but we can start at any point: we have a poor environment, a poor environment usually leads to risk behaviors or is related to risk behaviors, usually evidenced as lack of control, lack of control of one's circumstances and one's destiny is now acknowledged to be a broad risk factor for disease. So this is the quincumse of powerlessness of which we have been talking about. Now biological powerlessness is part of that pattern, the mold of powerlessness and any effective approach to AIDS is one which breaks that pattern.

For the powerless, there are two potential paths to empowerment: the individual and the collective. Now. individual empowerment is attained through self-esteem, skill-building, satisfying basic needs, and developing social contacts. Collective empowerment, however, is synonymous with community organizing for large-scale social and environmental change. Unfortunately, the programs that we see funded and pursued today tend to focus on the individual because they follow the medical model. In fact, most social services in the United States adhere to the medical model, and believe that treatment of the individual is the only answer to solve this problem. When we're trying to move away from that reductionist model, and we're trying to look at community-focused health, we have to be very aware of the fact that there are many possible pitfalls, and I have identified some that I want to share with you. Because I think that we have suffered from all of them in our experience in AIDS.

First of all, I don't have time here, and I'm not a sociologist, to give a position of the process by which the gay community of the United States had begun to empower itself before the AIDS epidemic started. But I want to point out that the gay community had received the legacy of the civil rights movement, and its own incipient gay rights activism immediately prior to the advent of this epidemic. Now the gay community, when faced with the epidemic, applied its not insubstantial skills, gifts, and assets to the crisis before it, and in great measure filled the vacuum that the state, to this date, refuses to address satisfactorily. Now as the demographics change, the gay community, recently empowered, faces another challenge. Still new to the exercise of its hard-earned and still-insufficient power, it must face the prospect of relinquishing the control of scarce resources, and sharing its leadership with other affected communities.

These other affected communities have their own history, and their own patterns of powerlessness, oppression and discrimination. Unfortunately, to a large extent, these communities also share in the generalized homophobia of the dominant culture, even as the gay community shares in the racism and classism of those who oppress it. Then the struggle of these affected communities, gay, African-American, Latino, Haitian, Asian, and Native American, to collaborate for the development of greater resources to address our common problems, and exercise our power. It's a situation that brings into focus among other things the very definition of community, and also necessitates a fresh approach in addressing health.

Now, when we speak of community-focused health interventions, we have to avoid these pitfalls. The first one is a pitfall that I call definition, for lack of a better term. Community is affinity, it is geography, and it is organization. If people are not coming together to share their experience and transform it, there is no community. There can be affinity, there can be geography, but without organization for change, there is no community. We hear a lot these days the word 'community' bandied about like it is going out of style. In fact it is used more often than empowerment. We talk, I have heard people talk about the diabetic community as if the condition was enough to warrant the use of 'community'. In the same sense there are other people who talk about the HIV community, and although there are people with HIV who are indeed part of a community because they are addressing their issues and forcing change, it is not because they are HIV positive that they form a community, it's because of their organization. So we have to be careful with that, and not presume that because people are HIV positive or that people are HIV negative—that's another one that's bandied about a lot, the HIV negative community—I guess we're all trying very hard to be positive, I don't understand that one. We have to stay away from the era of defining people simply because they have something in common.

The second pitfall, and we have suffered from this one for centuries, is tokenism, which is very briefly defined as participation without authority, and I am sure that many people in this room are intimately familiar with tokenism.

The third is bureaucratization, and here I'm referring to deflecting community energy into managing functions. I'm also talking about turf wars between agencies. And I am also talking about the self-preservation needs of institutions and agencies.

The fourth one is antiprofessionalism, and here I'm referring to romantic simplifications and naive assumptions about skills. Just, I believe it was Wednesday, we had here in Boston visit by a man who I admire very much but I who I think is guilty of oversimplifying a lot, his name is John MacNight, the author of the famous phrase, 'resources and power services', and unfortunately I think that we see, particularly in the health field, that one cannot be absolutely antiprofessional because then no amount of organization is going to fulfill very real, very concrete needs of the community.

The fifth one I think is reductionism. Now I label this like that, although I would also be willing to call it extreme decentralization, and I think it shows an abandonment of policy for an exclusive focus on immediate issues without substantial control over economic resources, of all the resources that are necessary to promote the change that is needed.

The sixth one is privatization, although we could call it the 1000 points of light syndrome. It's turning self-help efforts into voluntarism and charity.

The seventh is reactivism. It is when communities or individuals are placed in the constant reactive mode, in a crisis mentality, with no focus on social change strategies. And I think that we saw a lot of this in the beginning of the AIDS epidemic, and in fact we still hear a lot of people who are in crisis mode after 11, almost 12 years of a pandemic. If we are going, I am not saying that it is not critical, but we cannot be reacting in crisis mode all the time. In fact perhaps the best known agency dealing with AIDS in the first years of the epidemic was called the Gay Men's Health Crisis, and I think we still retain a lot of that crisis mentality that does not allow us to build programs, design and implement programs that are long-lasting and that will have significant effects on the future of epidemics.

And the eighth and last of the ones that I have found important is individualism.

It's one the self-help people restricts to a personal level issues that have both personal and political dimensions, and I think that, unfortunately, our government at the federal level and at a state level here, are great examples, I would not call them brilliant, except to make a point of the points of light, examples of that tendency to reduce to the lowest common denominator and to the individual plane everything that happens in a society, and to eliminate all possibility of dealing with the political dimensions of a problem, such as the AIDS epidemic.

Now, if we're talking about community-focused interventions in AIDS, some of us in the field suggest that a socially-competent learning theory approach must recognize the reciprocity of community-individual relationships. There is a tendency, because all theories are culture-bound, to view the individual as primary, and the community secondary, or as an extension of the individual and her or his relationships. But in other cultures that does not happen in that direction. The movement is from the community towards the individual. So a culturally competent understanding of social learning theory that accommodates for these divergent views

of the primacy of either the individual or the community should recognize the reciprocity of those relationships and simultaneously seek to enhance collective efficacy, promote consciencization, induce behavior change, and change the environment. If any of these four are missing, I submit to you that the program cannot be truly effective.

In fact, if we look at the quincumse of empowerment, what we find here is again concientization, we change the environment, change behavior, and self-efficacy that drives the whole process. Now, we know in particular that when we're dealing with an epidemic that has known modes of transmission, behavior change becomes extremely important, because risk reduction rests on those behavior changes. Now. behavior change, once again using the pattern that we have been using this afternoon, requires initiation, which consists both of induction of the behavior change and motivation for the behavior change, that leads to action, action which requires skill-building for the individual and social supports, so the individual can actually perform the action, maintenance, so that neccesary adjustments are made to sustain the behavior change, and a concept that may not be completely agreeable to a European or Eurocentric liberal tradition, but which we find more and more necessary, is social enforcement of behavior change, and I would like to finish here and then I'll go back to social enforcement, then what completes the quincumse for behavior change is the stage of normalization where we have evidence that this behavior change is now somewhat permanent by looking at the permanence of the change itself and the permanence of the social network that support that change. This is how we can see if the intervention is appropriate. And of course within this quincumse, then the normalization, the permanence of change and the permanence of social network, becomes in itself the inductor and the motivator for behavior change in individuals that are not yet part of this loop.

Let me go back a little bit to social enforcement. Recently we had a meeting at the Department of Public Health in which we were discussing results of some research going on at the Fenway Community Health Center, which clearly establishes that among the main causes of relapse into unsafe sexual practices is excessive alcohol consumption. And we brought up the question of social enforcement, because it the same bars that are willing to promote condom use, that are willing to promote safer sex workshops, and that are willing to display all sorts of paraphernalia and propaganda, however tasteful or untasteful, are still willing to serve excessive amounts of liquor to its clients. There is a need to begin applying some social enforcement techniques, so that people within the community have some protection, and have a measure of a safer environment in which they can move without additional risks that will produce unsafe behavior and will cause relapses in risk-taking. The notion of course is not one of creating the AIDS police, or the risk-reduction police, but it's one of clearly giving the message to places of business and other such establishments that these activities are not highly regarded in the community, and that places that continuously engage in those activities may be subject to some type of community retribution, such as the withdrawal of support, of economic support. These are things that are done constantly in other areas: we have boycotted grapes from many places, we have stopped drinking this or that wine for many political reasons, we have done very many things that fall under the rubric of social enforcement, and it is also time that we start doing that in order to help people protect themselves.

Now, the process of behavior change, we have said, is not linear. And unfortunately many of the interventions that are funded today have a very narrow and linear view of what happens. They basically talk about the usual model of primary, secondary, and tertiary prevention, where you have preinfection interventions at the primary level, infection or recent post-infection interventions at the secondary prevention level, and tertiary prevention, when there are already symptoms of disease. What is needed, and I don't know if everyone is going to be able to read this entire matrix, is a community-focused AIDS intervention matrix, and I must give credit here to Haddon who came up with this idea for a vehicular accident, that we talk about levels, not only of primary, secondary, and tertiary prevention, but also at the impact levels in the individual, the community, and the environment. And we start addressing preinfection, not only in the individual, but also in the community and in the environment, and if we look at the columns we can see very clearly that it is usually the community intervention which is able to secure the environmental support for the individual intervention. As long as we are trying to provide only this column here, it is going to be very difficult to prevent infection, to provide the necessary services after infection occurs but before disease develops, and even after disease develops.

Now we come back to the quincumse for a very, I hope, obvious reason at this point, and it is that communities cannot be taught from outside how to do things, in the same manner that they cannot be told from outside what their problems are, nor what their skills, their assets, and their gifts are. We need support, we need resources to develop competent programming. Many people believe that when we speak of culturally-competent interventions, we are talking about culturally-sensitive or linguistically-appropriate interventions. In fact, it is my belief, my personal belief, that most of the interventions in AIDS have started out being culturally incompetent even when aimed to serve white gay males. In fact it is because they were culturally incompetent that large, gay-dominated organizations exist today, and will continue to exist for a very long time to serve that population.

Culture is more than folklore, it's more than outward appearances. Culture includes many things, but it basically includes values, beliefs, and assumptions, and until and unless programs identify, validate and incorporate these values, beliefs, and assumptions in the design and implementation of the programs, they will remain culturally incompetent. We have gone through the period of cultural sensitivity, which we define, a little bit cynically, as the will not to offend. This was the age when we were finding out that blacks do not like to be called other names, or that some Latinos prefer to be called Latinos and not Hispanics, and so on and so forth. We went through that period. Thankfully--in some areas of the country it's still going on-- but thankfully in Boston w'ree almost out of it. Then we moved full-force into the cultural appropriateness movement, and there we were talking about basically translating things into the appropriate language and the appropriate literacy level, and of course if it was for the African Americans we would make the whole thing into a poster that was red, green and black, and if it was for Latinos it would have to be some bright color, preferably yellow or red, and some music thrown in for good measure, and that was nice, but the programs remained as culturally incompetent as ever.

Hopefully now we will be moving from culturally competent programming, incorporating the beliefs and values and assumptions of the target population, of the service population in the design and implementation of the program, and eventually this will help all communities, even the dominant community, to access, design, and receive the services that its own power claims from the state and from the rest of the community. Thank you.

David Satin:

That’s a elegantly outlined program, a matrix into which to fit the specifics of dealing with this particular community problem.

Calvin J. Cohen, MD, MS

Research Director, Community Research Initiative of New England; Principal Investigator, International Observational Data Base Project, AmFAR Community Based Clinical Trial Network; Clinical Instructor, Harvard Medical School

Introduction by David G. Satin, MD

To speak about research, clinical research and the clinical application of research, we are fortunate to have CalvinJ. Cohen. Dr. Cohen received his bachelor's degree from Cornell University, his Doctor of Medicine from Albert Einstein College of Medicine, and his master's degree in science from the Harvard School of Public Health. He is currently the research director at the Community Research Initiative of New England here in Boston, Principal Investigator of the International Observational Database Project, sponsored by the AMFAR Community-Based Clinical Trial Network. He's on the faculty of the New England AIDS Education and Training Center, and is co-investigator of the Harvard-Boston City Hospital AIDS Clinical Trial Unit. He's a member of the National Observational Database Project, the National Institute of Allergy and Infectious Disease, Division in AIDS Research, a member of the steering committee of the Community-Based Clinical Trial Network. He is a member of, aside from his more traditional professional memberships, a member of the International AIDS Society, and finds time to be clinical instructor at the Harvard Medical School. Present Calvin Cohen.

Calvin J. Cohen, MD, MS

Thank you. It's also my pleasure to be here and to be invited to participate in this discussion section. I think it's fair to say in building on this wonderful introduction that we have had, let me add a few points that we have as perspective. We now know, as a result of surveys of all the countries of the world, that this is the biggest plague in history. This is number one--we have never had a larger plague throughout our times, in large measure because people can travel through airline travel and so on, that we have the largest plague that we have ever had as a world community. We are currently in some phase, and I think that it is fair to say that we're probably still in the early phase, of the largest plague that has ever hit human history. You are all a part of it. You can tell your grandchildren what it was like to be in the largest plague so far to ever hit the planet, and how we all responded to it. It's also worth pointing out the US is a relatively small player in the world community. We have an estimated one to one and a half millions persons currently estimated to be infected with the HIV virus. We are, actually, as I say relatively small in a sense that the African continent, for instance, has at least six million persons currently infected. So at least in terms of world geography we are somewhere actually in the bottom tier. It turns out that at least in terms of looking at cases per 10,000 persons in the area that in fact the Caribbean has the highest impact of any place in the world. Bermuda and the Bahamas are higher than the US.

Another point to be made is that we are not done, that we now know how the virus is transmitted, we have a sense of that. We also know that we are not that effective yet at making sure that this virus stops transmitting. In fact we are well aware of populations in the world where transmission is in fact just getting underway, and that we are watching it before our eyes, in some ways lacking an understanding of the resources and the implementation in terms of combating those measures that we know could stop viral transmission. We could today make it so that not one more person became infected. But that isn't the case--we don't yet have that in place. And so this is not a static epidemic--we are still increasing in the numbers of cases.

Finally one last note in terms of then US resources: in terms of the US, the annual budget spent on AIDS research is currently $100 million, and currently one of the issues that we're facing is: how much are we spending, and is that too much? What about all those people with cancer, and are we spending enough on them? And maybe the people with heart disease should start attacking the people who are fighting for AIDS research, and maybe they're getting too much of the pie, and so on. To put the perspective of the budget into a larger sense, I would just offer that the annual AIDS budget $800 million, is less than the cost of one B-2 bomber, one B-2 bomber. So, depending on one's priorities, would determine if in fact that this is a large or a small amount of money. This in some ways is a paradigm where in the realm of then making analogy.

This is an electromicrograph picture of the virus infecting one cell in the host immune system. What the virus does is that it takes advantage of the immune system, it infects, it uses the cell as a machine, and for each virus, out pop a lot more virus, leaving behind a destroyed immune system, continuing it to attack after increasing itís numbers multiply. Perhaps this is a useful analogy to think of in terms of how the epidemic in fact is starting and increasing in populations as well. That for each person, the virus then takes advantage of that host, rapidly increases the number of virus, and takes advantage of behaviors that we are now aware of that increase the likelihood that the virus will increase the number of hosts that it can attack. It, in some ways, has the same biologic imperative that most living creatures do, which is to recreate itself, to reproduce, to make more of itself. Unfortunately, this is a parasite and leaves behind destroyer organisms in its field. That's what we're up against.

In response, then, how does medicine respond, both in terms of national priorities as well as local, community-based priorities. The patients came to us, and they said, “Look, we are dying”. We know that, once HIV infected, 90% of persons currently know that the natural history of this illness is a slow, progressive illness, during which time there is an increasing burden of minor illnesses, then major illnesses, and finally death, and that they came to physicians saying, “We need a partnership, we need care. You’ve got a large number of drugs in that book--how about trying some of them? If you’ve got things that are hopeful, I want to take them. I understand they’re not completely tested. I understand there is risk. I’ll take that chance. It’s my life on the line. And that if there’s a compound somewhere in the world that somebody thinks is worth taking for this virus, then I’m willing to try that, if only because it represents hope that I might stop this thing”. Because we know again, that without these kinds of approaches, we’ve got a sense of the natural history. And in some ways it doesn’t really matter which treatment approach we’re talking about, whether it is empowerment, coming into communities and saying, “We will survive,” or whether it was pills, or whether it was alternative treatments. In some ways, this sense of, “Look, we know what’s gonna happen without taking action, we need to take action now”, unfortunately we have built a bureaucracy.

This bureaucracy basically an FDA process of how it is we release treatments in our society. I am not--I put this slide purposely so that you can’t read it -- it is meant to feel like, be overwhelmed, that in some ways it is. Now this bureaucracy makes sense for most illnesses in which we have non-life-threatening conditions and many treatments available--hypertension, diabetes, arthritis. We have a number of treatments available in each of these approaches. They are not life-threatening. We have a dozen different treatments for arthritis. Do we need a thirteenth? If I’m a drug company and I have an idea, then we have set up a bureaucracy to make sure that that drug is both safe and effective. Very reasonable principles. Where did that come from?

Well, approximately thirty years ago most of you, of course, would remember that there was a pill that was being studied in England and then became available in the US for research to prevent the morning sickness of pregnancy. It was extraordinarily effective. It did the job. Women could finally tolerate pregnancy without this rather horrible aspect of early pregnancy—morning sikness. Of course the drug is Thalidomide. After a period of time, we saw that the mothers did fine, they had no side effects, but of course, you all know vividly from Life Magazine and what it did with pictures the outcomes--the lack of safety. And it wasn’t really because of any plan at the time, but really because of the bureaucracy, the slowness that our machines moved, that by the time the machine finally got around to reviewing Thalidomide and the application, these pictures became part of a public legend.

And so we became aware that in fact drugs do have very serious side effects, and that it is the job of our bureaucracies to protect us from the dangers of drugs, and that if a drug is effective, that’s not enough, it had better be safe, and that in fact all of these steps that we have built in are meant to ensure that we will not be abused by those whose interests are in profit-making, or for treatment, whether that's snake oil salesmen who would like to sell you something that works, or it's a drug company--all of them have as their motive, in addition to those motives of beneficence and doing good for society, since not all pharmaceuticals are entirely profit motivated, but indeed, part of their motive is profit, and so they would like to sell as much drug as possible as quickly as possible. And in order to protect ourselves against that, we have built a machine that makes that drug company jump through all of these hurdles, so that they will test their product over and over in more and more and more people, and first in animals and then into people, so that we will be reasonably convinced that we understand at least what the risks and potential benefits are of that drug, and then we can enter into the decisions as to whether it is worth taking.

Now that makes sense for arthritis and hypertension—we've got a dozen treatments, we don't need a thirteenth, we've already got a dozen, so we want every new drug to go through those hurdles. That makes perfect sense. However, if you are a person with AIDS, and you know that your life span is such that if you've got a promising compound identified, that by the time it makes it through here, you're likely to be dead. This is, of course, unacceptable, and the position of persons with AIDS was that they became highly aware, as I'll show you, of this process, of all the promising compounds that people were testing, and they basically asked us to rethink this, and they said, "Look, all of this makes sense, but not for us. I don't have the time to wait for safety proof. I don't have the time to be sure that this is 78% effective and not 32% effective. I'll take the drug. Let me find out, because if I die while you're doing this, this is of no use to me. This pyramid doesn't work. So how do we do that?"

Well, part of what we need to realize is that we do need some aspect of proof. Why is that? Well, because this is part of the problem. Not Dial-A-Jewish-Story, which might be a good treatment for HIV, or Spanish dirty words, which also come in handy I am sure, as I'm sure you could illustrate to us at various points, but this one right here. This is an ad from the October, 1991 Phoenix, the local newspaper, in which a local gentleman decided he had the cure, and he was available to sell it. This is not old news, this is still going on these days. And what would he do? Well, there are thousands cured, and of course you would hear about the cure for HIV in the back pages of the Phoenix, that makes perfect sense.

Why is that? Why would patients believe this, that somehow the doctor wouldn't know but the back pages of the Phoenix is where you'd find the cure. Why is that? Well, there are lots of reasons for that. You've already touched on most of them. Basically the idea is is that these cultures that were infected with HIV had no real reason to trust the larger physician community and research community. In fact many of them had already believed that these researchers probably created the virus, that probably somewhere deep in the Nixon administration there were some evil scientists that decided to get together and find a virus that could ultimately eliminate the undesired populations, and that in fact somewhere, somehow, they were effective, they were smart enough, and that they decided to release this thing. We already know that that is impossible, largely because noone in the Nixon administration is smart enough to create this thing. So that's clearly out. But that is the mentality that, of course, is around.

So of course the physician wouldn't hear about it, in fact they're out to get us too, those men in the white coats. And certainly there are legends of other cultures, whether it's Tuskeegee or other experiments, in which indeed, the men in the white coats were in fact part of the problem, and were part of the abuse, and so how can you trust them? And in fact you have to trust us, and so where would we talk to us? Well, we might take an ad out, a small ad, and of course there are thousands cured, and you have to be on some of these drugs, and you have to have this and you do need an MD just to give you a shot, no other reason, but just basically a tech who knows how to give a shot, and if you're suffering you should call him 9:00-12:00, only at night, out-of-town, call collect. It's interesting that this is underneath it, I didn't design it, but this is the back page. So, this is still what we're up against.

Now, why is this an issue? The issue is, is that not every compound is worth taking. We already know that there are lots of compounds that are interesting to test, and might be, some of them might be worth taking, some of them indeed might help slow down the process, but not every single one of those compounds is going to work. Not only that, but there are always snake oil salesmen, there are always people who are interested in fame and glory, whether it's through malevolence, or whether it's through just sheer misunderstanding of the principles of treatment, or whether in fact it's just good intentions, there are always people who are willing abuse and say, "I've got the cure, I've got the answer, just pay me". And unfortunately there are always people who feel like this is how you'd find the cure, and this is how they will take advantage, and there people who have the resources to fly all over, and to fly to Europe, and there's always a clinic somewhere either in Mexico or in Switzerland where the answer is.

Now, we don't want to dismiss all of these. It is fair to say that, again, some of those things might help, help meaning they help you feel, better, they take you out of the life in which you are not happy, they put you in a place where people take care of you, they are attentive, they want to take care of your needs, and they're doing whatever it is that they think, and it is fair to say that you all know that whether we call it placebo effect, or whether we call it the power of love, or whatever. What is happening, however, is that at the same time patients are dying of a pneumonia, called pneumocystis pneumonia, and while this antiviral might decrease the likelihood of that pneumonia, ultimately people were still coming in with the pneumonia and still dying with it. There was a drug, an antibiotic, that could be given that could be turned into an aerosol, and then when breathed in, could decrease the likelihood of that pneumonia. The government said, "Looks good, we'll put it on our high priority list", a year later it was still on the list and no action had been taken. Physicians said, "That's enough of this. Let's find out". People in the community had already decided this was worth taking, and how did they decide what dosage to take?

Well, there was no information, there weren't lab data, there weren't animal studies, so what they said is, for some reason the community standard was to take an amount, 30 milligrams twice a month. They also looked at the jar, it came in 300s, they turned the 300 into one pill, and they breathed that in, they broke up the vial into two halves, while they just gave the community standard 30. And they rapidly decided, "Let's do a trial".

Four hundred and fifty people with HIV agreed with their physicians that this was a priority. There is no placebo group, there is no group that is not getting anything here, and they all decided to cooperate. Physicians in the community talked to other physicians, respiratory therapists, and a patient collaboration within eight weeks, 450 people had been randomized, to one of these three doses, and within a year we saw that there was higher percentage of recurrent pneumonia than on the higher dose, where there was a less percent of pneumonia. And we learned, and the FDA learned, that this drug was effective without a placebo group, without large studies, without academic support, this drug was proved to be effective.

This was the birth of community-based AIDS research, in which we learned that, indeed, we could prioritize what needed to be taken care of, and we could do it. That you didn't need the men in the white coats, that research after all is not all that complicated, it's just asking a question and answering it. And answering it in an honest way by giving the drug and finding out what happens, so that it isn't people saying, "Come to me and I'll give you this stuff, and this stuff works". It's saying, "I don't know if this works, so let's answer the question. Let's flip a coin, a third of you get each of these, and let's see what happens".

It turned out that we guessed right and that this drug worked. Now that was the first compound. At the same time there are hundreds of compounds being identified all over the globe, each of which has some promise. There are people in Israel putting compounds into test tubes, and there are people in the States. As you can imagine there is an enormous rush to identify compounds that, when you put it in a test tube with the virus, slows the virus down and might be promising. Why would that be? There's a huge prize at stake for the person who finds the right compound. After there's a lot of fame and glory that could be found in finding the right compound, that could even make a dent, much less stop the thing in itís entirety. There's a large prize waiting for that person so a lot of people got into the act.

Now, how would you find out about that if you were living here in Boston? How could you find out what the people in San Francisco and Israel were studying? Clearly you couldn't read all the scientific literature, although indeed one day several years ago a patient of mine came in with a journal called The Proceedings of the National Academy of Sciences, not the kind of thing you'd find in your basic library, but a fairly technical journal, showed me an article, and said, "What do you think of this stuff? This is being researched in England. Maybe we should do this". And my only response was, "Well, you know, my subscription just ran out on this thing. I haven't gotten my volume of this. As soon as I get it I'll get back to you". The people are clearly scouring the literature. After all, it's their lives on the line. What would you do if your life was on the line, if you had one of those viruses growing in you? You'd probably spend most of your waking hours looking for somebody who had an answer for you.

Well AMFAR, The American Foundation for AIDS Research, decided that this was a noble effort, and what they did is that they catalogued everything from A to Z that looked helpful, and so from A to Z they would summarize what was known at the time. This is a few years old, and in fact as time goes on, as we've learned about more and more of the properties of each of these, they get more and more written up. So that each of these gets a page, rather than just a paragraph. But that a person could learn, quickly, from A to Z, every compound that has promise, and why it has promise, and then they can go to a physician and say, "You know, I've read about this stuff, and I understand it's a derivative and it might have activity against…" to which the doctor would say, "Huh? What are you talking about?".

Now, how do we create partnership? How do we go from, "There's this exciting compound, and I think it's the cure," to figuring out "Is it worth taking?". "I've got $100 in my wallet, what do I put it into? Help me choose. I've got this symptom. Is there anything left?". Well, yeah, actually there's a lot, and every single thing on this page represents hope. Every single thing on this page represents the possibility that I might not get any sicker than I am today, or indeed might get perfectly well, if only I knew which combination of all this stuff to take. And how do I sort this out? And if I live here, this guy provided a way for people to figure out where they could go to find out the research, so that if you lived here you knew that the research was going on in these centers. Now what if you lived over here, or over here. Is this good enough? Can we bring the research to you? Or do you just have to wait until these people do their thing, and they sort out the list from A to Z. Isn't there any way to participate?

Now, what else was happening in the community? Not only were they listing, but there were others in the community who were not just going to sit around and allow the lists, they had opinions. And one such group in San Francisco, called Project Inform, was quite opinionated. He told you not only what was being studied, but what you should take. In his opinion, these compounds are worth taking, these aren't, and in fact, there are no placebo questions anymore because he knew what was worth taking. And that was the decision that he had made. And why should you believe him? Well, he had a newsletter, he sounded good, and what did he do? He addressed again that sense that it's us against them. The use of placebo occurs not out of scientific necessity, but in response to economic interest, the profit motive, knee-jerk thinking of the FDA, and misguided scientific dogma. All those people don't know what they're doing, they're out to get you, they're just wasting time, they're waiting for you to die, they're just waiting for the body count, and you don't have time. Trust me, take these things. I know that theyíll work. And he would in fact list the drugs and tell you how to get them. It's available, and you can write to this place and mix it up, and so on. Trust me I know what to take. Well, how do you know what to take? Or how do I know how to trust him? Who's this guy?

It turns out that we did a survey locally in Boston about this time, and found out that approximately a third of people in Boston were making their medical decisions not on what their doctor had told them but in fact based on what others had told them. That in fact, these newsletters, or other newsletters, or even just their friends who read the newsletters or whatever, that's where the most important decision was. The doctor was interesting—you'd go to him and find out what he thought, but that that was only one opinion of many, and in fact, all of these people might have the answer. There was reason for that, again the physicians weren't necessarily aware of the latest, they weren't reading all the foreseens in the national academies, so what would they know? This guy's at least reading all the journals, and maybe he's onto something. We had this dynamic, and those of you in back probably can't read it, so let me read it: "Happy birthday, big guy, from your old friend. I've been racking my brains trying to figure out what a fellow person with AIDS would want most, and then it suddenly hit me: why, it's an unproven AIDS drug. The perfect gift. The stuff turns mice blind, but hey, life's short". Hey, that's thoughtful. Now what is this dynamic? Again, the unproven stuff represents hope. The proven stuff--what do we know about it? Well, we already know that it's temporary, but that people die despite taking it. The unproven stuff might work--it might be the answer. Some combination of that stuff might totally do it, and if I do it on Tuesday and Thursday and I take this stuff, and I put it on toast, but whole wheat and not white, and it's gotta be the stuff in San Francisco, it can't be the stuff from somewhere else because they don't know what they're doing over there, it's gotta be the right people. How do you figure it out? Are we wasting our money, or is this the answer?

Well, we did two things. One was that we decided that as a community of researchers, that there was enough pressure on us on promising drugs that we had to come up with a way to release it. Not to go into detail, but again this is how we decide as an FDA when to release drugs. We approve them over here after they go through a number of steps. But they have to go through animal studies, early phase one, smaller numbers, phase two, larger numbers. If that's sufficient, you can approve the drug, but if it's insufficient, you have to keep studying. But if there's a drug that's over here, and again, the demand is high enough, that stuff looks promising and I don't have time to wait. So how could we do it? Well, you could enter a study. And in the study you might come out to be the control group. Remember, in every study you've got a randomization—you're either going to get the real stuff, the new, exciting, unproven answer cure, or the old stuff, the stuff we know doesn't work. And if you feel like that's not fair to you, that's not equity, then the control group is out of control. For those people thats not going to work. That kind of research is not going to answer their needs.

So we created something called a parallel track, and this process, actually just put into regulatory form just this month, allows an understanding that in fact some people would find that randomization fair, others will not, others will want to just take the stuff, and that we have a process that allows people to just take the stuff. How do they get it? Who decides that they should take it? Their physician, them and their peers. They will decide if it is worth the risk. We knew very little about the compound. The stuff could turn mice blind, and the stuff could shorten your life, it may or may not be worth it, you might die sooner if you take it, we don't know, it's still under research, but if you want to take the risk, how do you decide? Who are the trusted advisors? If you and your trusted advisor, and again, the physician is clearly, at least in this culture, the one who helps you decide which of these pills and things is worth taking--so if you and your trusted advisors, whether it's peers and/or your physician, can agree that at least will remove that forbidden fruit aspect to it, the idea that I can't get it, therefore it's gotta be worth taking. So at least we'll make it so that you can take it, and then you get to decide is it worth taking since I can take it. And indeed that actually has been one major improvement we have in making sure that research is more fair. Those who enter the research are doing so not to get the good stuff, but because they feel that that's a fair question for them to answer.

Finally, we need radically wider testing of AIDS drugs. We've got a lot of compounds, as I've shown you on that list, and we've got an academic framework in which those drugs do get tested, but they do it one at a time, and they do it for a while, and each drug testing takes years. And not only that but they have the bias of all academicians, which is to say that the molecules that have been developed from the molecular physicists and the molecular biologists, those are the things that have the most promise, but what about the cultural approaches. For instance, what about acupuncture. Acupuncture is considered in this country an experimental approach. It has been around longer than any chemical that we are using that we consider proven. Acupuncture has 5000 years of clinical proof that it works for some things, and yet here in this country it's still an experiment. Why? Because we haven't proven it. Obviously in other cultures that isn't the way you do it. You do it because your forefathers and the cultures who've used it before you have their generations of proof that say these things work, do this for that. There isn't any data, there's no double-blind control group, but do this because it works.

Do those things work? How do you convince anybody in the States that it works? It is worth testing at all? Are we ever going to get those things tested? Well, are there other approaches that are worth testing? Are there other innovative approaches, other than antivirals? Can we support the immune system in other ways? Are there compounds that we can identify that just somehow support the immune system, that aren't developed by molecular biologists? Can we target those infections, and try to prevent them, and not look for the big bang, the big antiviral that's gonna solve the whole problem, but what about targeting the specific infections themselves one at a time, as those physicians did five years ago? How are we going to do that? Who's interested in doing that? It's not going to be done at the National Institutes of Health--they are not going to study acupuncture as a treatment for AIDS.

Who's gonna do it are the people at the front lines, the community-based physicians in partnership with their patients. When a patient came to me and said, "You know I've had this neuropathy, this pain in my nerves in my feet and my hands, and it hurts. And I went to see an acupuncturist in Cambridge, and you know I feel better. And I feel better than anything you gave me. This stuff just seems to work, and now I don't need your pills". I said, "That's interesting. I trained as an acupuncturist, and I'm glad to hear that you found that beneficial". And then another patient came in with the exact same anecdote, "You know, I went to see this guy, and I'm better. The neuropathy doesn't hurt anymore". How do we prove that? Who's gonna prove that?

Well, after those kind of anecdotes it's going to be a collaboration of community-based researchers who hear these anecdotes and say, "Alright, is this real, or is this just thousands cured, take it now before it's too late? What's hucksterism and what's real? Who's the interest?". Well, a collaboration has come and it's now in fact part of the national model, albeit grossly underfunded, in which a collaboration of community-based researchers work together with the patients they see every day to identify the priorities that they share, the things that they face in terms of the threats to their health, and the approaches that they feel make the most sense, not necessarily because the molecular biologists identified this identify this as the most likely thing to work, but because of other things. Because enough people have said, "You know, this stuff is working". And even if the physicians say, "You know, I don't think this stuffís gonna work. I think you're wasting your resources". Maybe it's worth the research to prove it, maybe what I need to do is disprove a medication, as well as prove them. And indeed that has been one of the outcomes of community-based clinical trials is in fact to take a look at what's in widespread use in the community and to find out if these people are wasting their money or not. Because one of our priorities is in fact to help people conserve their resources and use those things that help, and at least identify those things that in large numbers make the most difference. And so, instead of just anecdotes of, "My friend in San Franciscoís taking this stuff," it becomes, "Alright, why don't the next 30 of us all take this thing, and why don't we record our CD4 counts, and why don't we record how we do, and let's just look at over time, and let's find out".

As a result of that approach we have discarded a few medications that a few years ago were indispensable to PWA's and their support groups, two compounds, the names of which aren't important, that groups in buyers clubs would send people, take lots of money, give it to one guy, send him over to Japan, suitcases full of this stuff, bring it back, distribute it, lots of money. Why? Because somebody said this stuff might work, it works in a test, it's probably going to work in you. It's unproven, so it's gotta work. And indeed we decided to find out, and in fact it doesn't work. We can service not only the assumptions and disprove medicines but in fact prove them.

As a result of community-based research we have not only tackled acupuncture, which I've already described to as a treatment for neuropathy, and we have the first evidence from our trial that indeed acupuncture can decrease if not eliminate, can decrease the amount of nerve pain, and increase the amount of sensation a person can feel with HIV-related neuropathy, but that, as a collaborative network of community researchers around the nation have studied a particular antibiotic to prevent one of the most life-threatening infections, an HIV infection called MAI, which is a cousin of tuberculosis. In collaboration of sites around the nation and the sponsorship of a drug company who believed that this approach makes sense, and wasn't getting any interest at the upper echelons of academics, found that community-based networks were willing, participated, and indeed two years later we now have proof that this life-threatening infection can be prevented, and can be prevented to the tune of a 50% reduction in the amount of infection that a person with AIDS would face from that particular organism. That's where we've begun.

Other trials are going on to investigate other alternative approaches as well as standard approaches, gender-specific approaches, but not only that, but then to address how testing gets done. As the point was made eloquently, research can only get done in the community when there's a partnership of trust and belief. If you don't trust the guys in the white towers, no matter what they're studying you're not gonna take it. It just doesn't feel like you can trust those guys, and indeed there are many people who can trust them, people who felt that they were part of a community in which this came from, but others who didn't, whether it was for geography in which you just couldn't get there, "Why should I drive four hours every day to get there?" or in fact you were local but you didn't feel like these were your people, and "They're not on my side, and their systems don't make sense to me and I don't trust them. I trust my doctor in my clinic, but I don't trust these guys". And Tuskeegee keeps coming back in all of its manifestations in all the different cultures as a sense of mistrust of the investigators. As a result, the community-based research model, of which CRI is one example, works on decentralizing research, in which, instead of you coming to me, I bring it to you. I bring it to your physician who hopefully you've developed at least some trust in, whether it's your physician or your health care team, some trust that this person has your interests, and not the drug company's interest, but your interests, and you can trust that person. And so that the research can be translated through our team of people in which we have translated what it means to be in research, what does it mean to be randomized, what does double-blinded mean, and how does one understand that in the way so that a culture can then understand it and feel that this is part of what they need in order to separate wheat from chaff. Then in fact instead of just taking everything we want to know what's worth taking, and be a part of the process of solving it.

And so by bringing research to clinicians, to community health centers around the state and indeed throughout New England, we are proud to say that again the CRI has been the fortunate recipient of an innovation in the state of Massachusetts, the Massachusetts AIDS Fund, in which on your income tax form for the past two years there's been a box that allows you to donate money voluntarily to a tax fund, and part of that money the state has donated specifically and earmarked specifically to AIDS research done in this way, so that people throughout our state can participate in research and not just wait for the people in Boston and San Francisco to find out what works, but to participate in defining the questions and getting the answers. And so the geography and culture and the waiting time no longer need be a barrier, but by creating a partnership we can be part of a solution, not that every drug will be a winner--some of them won't, some of these things won't work--but at least we'll be a part of the process of figuring it out, so that when I go to my doctor and I say, "Look, I'm dying, give me the drug," I'll at least know that we're either finding out if the stuff is worth taking, or that we've figured it out that it's worth taking. And that indeed is part of what patients are coming to us for, is finding out what's worth taking. Not just a list from A to Z, but what's worth it.

So on that note, let me conclude by saying that community-based research is quite, has been part, definitely part of the fabric of HIV research. It is quite clear that it's an innovation. Nowhere in the history of medicine has there been such an exploration of different ways to get answers, and we hope that it continues to be part of the mainstream of research for all communities.

David Satin:

Thank you to Dr. Cohen. That's a unique presentation of research. It's not my experience. It's not presenting new research and new findings, it's presenting a new way of researching, and as such it is truly social change, and as you pointed out it follows nicely from Mr. Parkhurst's discussion of a community validating itself, supporting itself and gaining support from other communities, in this case the research community, which is a part of the patient community.

Judith Kurland

Commissioner, Boston Department of Health and Hospitals

Introduction by David G. Satin, MD

We now are privileged to hear about the public policy aspect of dealing with this AIDS plague, and how public policy deals with, responds to and deals with the community in need of social response, and the community trying to reach out to give that social response. We will hear from Judith Kurland, who attended Mount Holyoke College, and is currently Commissioner of the Department of Health and Hospitals of the City of Boston. She was in the past Vice President for Strategic Planning of the New England Medical Center, as well as a Director and Chief of Staff and Legislative Director for both the Lieutenant Governorís Office and various congressmenís offices in Massachusetts. She is Adjunct Professor at the Graduate School of Communications at Simmons College, and a member of the advisory board of the Graduate Program for Health Studies, and is an Instructor in Community Health at the Tufts University School of Medicine. As you might expect from a busy lady who has this important public position, she's a member of many boards and organizations. Let me pick out the ones that are most relevant in my thought—the Massachusetts Health Research Institute, the Health Action Forum of Greater Boston, the Harvard AIDS Institute Advisory Committee, and the Boston Committee on Access to Health Care. Let me present Commissioner Judith Kurland.

Judith Kurland

Thanks. Good afternoon. I was asked to talk a bit about AIDS and public policy and what the trend has been in public policy and some outlooks, and I think people always want to talk about what is unique in the public policy approach to AIDS or how the uniqueness of the epidemic has affected public policy. I'd like to point out both how it's unique and how it is not, how it's been somewhat special and how it's been everything the same. AIDS has, many people have said this before me, has pointed out the strengths and the weaknesses of the health care system, and actually, after previous speakers, I don't need to mention…anyhow. The strengths are that we are very good at acute medical care, curative care, we're very good at high technology, and we're rather good at research. We're extraordinarily poor at prevention, at education, at behavioral change, and almost nonexistent in terms of community-based services and community-based, and as Nicolás said, appropriate services. I think that the AIDS epidemic pointed that out, and I think in some cases it has overcome some of those weaknesses and utilized some of the strengths but in other ways not, and I will get into that a little bit later.

The other thing that's been talked about in terms of the unique quality of AIDS is in terms of the mass mobilization and quick response to the epidemic. I always find that rather interesting because I think from about '81 to '87 there was almost no response to the epidemic. People were doing things, there was some research, there were some articles, but I wouldn't call it a massive mobilization. But it's interesting to me that that's the perception—that there was massive and quick mobilization, and a unique outpouring of interest, support and dedication to doing something about the disease. There have been major changes, and the mobilization and community pressure have made things different in terms of AIDS, and certainly the previous speaker, in talking about the fast-tracking of research, and application of drugs is one of them, the relatively quick funding toward the end of the 80s in terms of research money, the Medicaidization, but having everybody, a lot of people become eligible for Medicaid relatively early when they became impoverished because of AIDS, some attempts to do community-based education, I think those are indications that there are some things different and interesting, and a response to mass mobilization.

Now on the other hand again I would argue that we were very slow to get to it, that when the communities identified at risk were not just gay men, but gay men that were considered a minority of the gay white male population, that is those that might frequent the bathhouses of San Francisco, and you should go back and remember and think about what the first characterization was, it wasn't ordinary gay, white men. It was gay, white men who had excessive behavior, and Haitians. So when it was those two populations, there really wasn't the kind of mobilization or interest, and neither was there the kind of tolerance that we saw later, so I would argue that perhaps that mobilization and even empathy for people suffering from the disease did not exist. I would argue that we still spend most of our money and time on the curative end of the epidemic, that there is a lot of money for acute medical care. Because Medicaid now covers a lot of people we have not changed the nature of our response to the disease.

If you look at the Ryan White bill, in itself a model in terms of a response to community pressure, a response to interest, and I would argue very strongly, a very enlightened approach to community-based planning and trying to involve a whole host of people in the community -- providers, recipients, all the affected populations. I think the approach required under Ryan White is very enlightened, but if you look at where the money is going, still a disproportionate share of it is going to cure people, in a disease that, until very recently, was considered acute and terminal, as opposed to what we're finally seeing, which is a kind of chronic, terminal disease.

The money for education is relatively limited and always constrained by sexual taboos, which I'll talk about a little bit later, but we haven't changed the nature of our medical care or health care system because of it. In addition, there is practically no money and very little interest in the kinds of support services and other services that people suffering from AIDS need to have, such as housing, and transportation, and social support or income replacement. So we continue to be willing to spend a lot of money on institutions who provide care to people, i.e., hospitals, and now some other, but we seem to be willing to put money into the institutions that are run by people who we can trust, as opposed to empowering and distributing funds to people who perhaps don't look like the people giving out the money and don't know how to write research grants.

We have also, I think one of the interesting things that needs to be discussed around the issue of AIDS, is the one that people have the most difficulty discussing, which is the balance of traditional public health concerns and both the issues of confidential and privacy for individuals, and the civil liberties of individuals, which are different. We have a very hard time discussing that, I would argue in part because we have neither the vocabulary, really, in the United States but probably more likely we don't have the trust that people making…trying to get reason to argument aren't really trying to effect some change, such as quarantine, isolation, lepers colonies, loss of jobs, public humiliation, and it is a very important thing as the epidemic grows and as the epidemic grows to people who are less well-organized and I would argue much more vulnerable, that we have the ability to have an enlightened and honest discussion about this.

Even if you think about it in terms of whether or not AIDS is considered a sexually-transmitted disease, well, that's almost a ludicrous thing to say, of course it's a sexually-transmitted disease, and yet if you think about it, a number of states have refused to classify it that way, and there was a great reluctance because sexually-transmitted disease usually called for things like mandatory testing partner notification, and when you think about the loss of jobs, housing, family, benefits of all types, there was a great reason not to do that, and yet we haven't figured out a way to reconcile the fact that this is a sexually-transmitted disease, and approach the treatment and the handling of the disease in such a way.

Much has been made about the power of the gay, white community in organizing resource toward AIDS, and I think one of the public policy decisions and discussions that has to occur is that as the disease moves to even less empowered populations, and I don't want to have an empowered versus an unempowered, but an even less empowered populations--IV drug users, women and children of color, particularly, immigrants—it seems to me that the public policy debate is starting to shift again, and it's shifting again into the innocent versus guilty kind of quality, classification.

In the very beginning of the epidemic, again, when the affected populations are believed to be gay outliers, if I can use that term differently, gay outliers and Haitians, and the innocent hemophiliacs, there was a lot of movement about, “what do we do about this, and what do we do about them?” When the understanding that this was a virus and could be transmitted came through there was much more tolerance and less pressure to do something about them because the them could be us, because we didn’t quite understand all the methods of transmission, and how limited that might be. And I think that that is going back and forth again, that now that we understand how the disease is transmitted, or most of us believe we understand, although there was an interesting article, Newsweek or Time, recently that was interesting, from an AIDS activist about do we really know, that shows I think the kind of underlying concern that was referred to earlier, that was this a plot. Actually I think the Nixon people were smart enough to do this, but I don’t think they did, and I’m no fan of Nixon, I just think they were more clever than they thought, not as clever as the foolish Reagan, who’s now made it impossible to fund social services for the next decade. But I think we’re going back and forth on the “could it be me or mine, or could it not be?”. As that doubt or as that assumption changes, our policies tend to change.

For instance, there wasn’t a big move toward testing for a long time, as you recall, and now once again we are having a very strong movement for testing because of the concerns of police, fire, emergency medical technicians, other people that might come in contact as innocents with people that might be infected. It’s a very interesting kind of debate. I haven’t heard anybody say, “Did it ever occur to anybody that if you test somebody after he’s been exposed we don’t know whether or not he’d been exposed all along?”. I mean the foolishness of the debate is really quite frightening, but I think that reflects the fact that we can’t have, that we haven’t been able to figure out who is innocent and who is not, and there’s been a lot of talk of the use of the use of that term, and we’ve talked about innocent victims, i.e., someone infected by a dentist is an innocent victim, and anybody who might have done anything that might have brought the disease on himself or herself was no longer innocent.

There’s also a great move, for instance, to test prisoners. I found it interesting that the governor of this commonwealth who walks a very interesting line between extraordinarily right-wing and progressive on some social issues, wants to test prisoners, but not give out condoms in prisons. I don’t know what to make of that at all, and I also don’t know why being sent to jail for larceny should be a death sentence, and yet that’s what it is if you’re not going to provide condoms to people.

I think that the uniqueness of the way in which the disease is transmitted combined with its terminal nature has reduced some barriers, some social barriers, for instance, I don’t know how many of you ever ride the New York City subway system, but those of you who ever have will remember the advertisements all along the top, and I saw extraordinarily graphic advertisement in the New York City subways about condom use and about the gay lifestyle in Spanish. I think that we've seen comic books addressed to teenagers that we would not have seen before, and that these are not hidden behind the shelves of a drug store, they're given out at respectable community-based organizations. We see ethnic populations that have never been able to talk about female empowerment, or the lifestyles of men, for instance, things like bisexuality, are able to do that now. We have needle exchange not only being discussed but actually again being proposed by a governor that I would consider phenomenally right-wing. At the same time, and I feel this one pretty strongly and personally, it's hard to talk about providing condoms to adolescents in the schools of Boston when the STD rate of children of color in those schools is going through the ceiling. We have not been able to break through the notion that there are competing goods and rights, and that protecting or saving life is perhaps not as important as teaching children lessons, and I don't think that we've broken through that, I think that the taboos of our society have not been that strongly affected by the AIDS epidemic when it comes to those we hold most dearly and tightly.

There's a lot of talk about how the unique mobilizing quality of the AIDS epidemic and the particular strength of the gay community that first organized, that it is a relatively well-off community, a community of people that look like the power brokers and the congress and other places, people that were trend-setters, style-setters, people who were much-admired would become the victims of the disease allowed them to mobilize and to produce the kinds of results that other populations could not do. I actually think there's a lot of truth in that, but I think what is underestimated is how the absolute terror that nobody was doing anything about the epidemic in the beginning empowered people and organized in a way that did not exist before. I also think that it's true that the gay community did not have a social and medical institution that most other communities have.

So there are not a whole host of social service agencies as there are for the African-Americans and the Latino community, or the Hispanic community, or any ethnic communities. There are not the kinds of community-based organizations and providers of service for the most part, except in places with large concentrations, long-time large concentrations, of gays and lesbians, they might have some clinics, but other than that there was not the network of services and network of connection in the gay community, so it allowed the gay community to mobilize around this disease, and in fact was the cause often of a great political mobilization.

The communities that are now affected in addition to the gay community often have a list of problems and needs in addition to AIDS. They are not so centered, and they are not so focused, and I think that is a problem in terms of organizing, and also I would argue that they are even less empowered than the gay community, and often by far, and so there is not the kind of protection, and there is not the spokespeople often for those communities if of the communities themselves, are often disempowered, and if not of the community often really don't reflect the needs of the culture of the community that they are supposedly trying to protect.

Well, where are we? I said in the beginning that AIDS identified the strengths and the weaknesses of the healthcare system, that we are good at acting fast, that we are good on high-tech and research, that we are relatively terrible on changing behavior, on educating, on prevention, on community-based services. Well, I think that we have made some strides, and, well, I actually think that we have stepped forward and stepped back on almost every level of community empowerment, and in terms of us versus them, I don't know where I would come on this. I am a great believer in large, symbolic efforts when they capture the imagination of the people. I think the quilt did more to make the American people understand who was affected by AIDS and that these are human beings, they're people, with family and connections and friends, than almost anything else that I have seen.

So some of the us versus them has disappeared, as Gene McCarthy said about Vietnam, when the children would come home in coffins to the court houses and center squares of the small towns of America then the war would end, when people realized, and every one of us knows someone who has died or is dying of AIDS, and I think that has changed the us versus them, but it hasn't, and when you see the cries for testing, and when you see the kind of punitive language and the cries for testing certain populations--prisoners, newborn babies, because they are innocent, but their parents aren't, I'm not so comfortable that the us versus them has been overcome, and I can't help but believe that a lot of it has to do with the growing color of the victims of the epidemic, and I think that it's easier because racism is a fact of life in America, who marginalize and try to separate people of color, and the epidemic is growing in the people of color, so I'm not very comfortable about the us versus them, although I think there is greater tolerance and sympathy for the individual.

I think we have not overcome the experts and the establishment versus the community-based initiatives, even with community-based research effort, even with ACT UP, even with AIDS Action. We have a great ability in the United States to institutionalize newly-empowered groups, and make them part of the elite and part of the establishment, and keep everybody else out and everybody else down. I think we do that relatively well, and I think what we have done is that we've encouraged the community organization to come into the establishment. I think it's being done on the research side, I think it's being done on the clinical side.

That doesn't mean that I don't believe that the research methods and the research establishment, that wonderful graph, I love graphs that show you that you can never get anything done, have changed. I think they have changed. I think the nature of clinical care has changed for people with AIDS. I think there's much more continuum of care. I see that in the institutions that I run for the very fact that all the institutions are involved--from the public health department, to the acute care hospital, to the long-term care hospital back out to the community hospital, so I see a continuum of care, and I see, for instance, a huge effort to keep people out of the hospital, which is appropriate for everybody.

We're just doing wonderful things in terms of people with AIDS and changing the nature of who the caregivers are, of the diversity of the specialties brought to bear, the thoughtfulness about social services and home services and advocacy, and education and thinking about the whole family or support structure for patients—we're doing that much, much better, and I think it's affecting the way that we're providing care for people with other diseases, so I would say that that's been a great stride. But almost always there needs to be a hospital or acute care intervention before anything kicks in, and that is wrong, and that is a great failure of American medicine, and we have not addressed that, and we haven't figured that out at all. We are pushing the care out to neighborhood health centers, out to primary care physicians who now feel competent, I think because of a lot of efforts to treat people with AIDS, whereas before they sent them over to the teaching hospitals, but I don't think that we've really changed the locus of care sufficiently, and we certainly, I will tell you even in the percentage of referrals to hospices that we haven't yet accepted the fact that people are dying.

We are starting to deal with AIDS with heroic efforts, time and time and time again, the same thing that we do with very elderly people, and with babies with no hope. The people that run hospices for AIDS are shocked at how few referrals they get, and how then people want to send them patients, not when a hospice is supposed to be used, to help people get to die, but really for the last two or three days, which is not what a hospice was designed to do, so I don't think that we've accepted the fact that heroic efforts are not necessarily appropriate, wanted or even... I don't think that we've particularly changed the fact that we give money to institutions and not people. I don't think that we've changed the fact that we give money to people who have a track record in medical care or research or grant writing or are bonded, and won't walk away with the money and have big-name accounting firms to do their audits. I don't think that we have crossed that bridge. We'll do it in a little bit, and each of us, I think, in large organizations tries to do it, but I don't think any of us see an extraordinary amount of funds going out for AIDS, and the approach to AIDS that we really are willing to change the nature of the power relationships, and power relationships go to institutions, and they tend to go to physicians, and they don't go to people, or non-credentialed people.

I think that the notion of empowerment is going back and forth with all of this. I think a lot of groups are more empowered than they were a long time ago, and nice articles have been written about there will be more money for breast cancer research because of the mobilization on AIDS, and I think that's true. I think that each time that a vulnerable population, a disempowered group, accomplishes something, other vulnerable populations or disempowered groups learn something on how to do it. The great problem is, I mean we've all heard it in the arguments there's too much money going for AIDS, and that the argument is always put up against, and I find it interesting, against money for breast cancer, as though that's the only pot that we all have to pull from, and we're the only two populations.

I used to work in Washington in Congress, and I used to tell people that came to see me that NIH research money went to the diseases that occurred in middle-aged, middle-class white men, because that's who the Congress was, and they passed the funding, I mean, it was not a big surprise, and nobody should have been shocked by it, but of course that's where all the research money goes, and that's where all the treatment money goes, and it hasn't really changed that much, and I think to, in a sense, keep the amount of money for which the disempowered or minority populations have to compete is faulty. Yes, it is the… list, and the price of one B-1 bomber, but people really, even a lot of people, progressives and people on the left, no longer even make that argument because they've lost that one so many times. It gets to the point where we should be winning—we're at the end of the Cold War, people seem to have given up on it.

So although I do think the unique organizing nature of constituencies around AIDS has empowered others I'm not so sure that we are all that much empowered because we have not changed the control of the resources. And lastly, I do want to come again to the issue of how do we address unmentionable subjects? How do we get a conversation going about the need of unknowing partners to know that they are at risk balanced against the need of those who are afraid of losing their jobs, their homes, their friendships, their networks? I think it is a conversation that must be had.

There is an interesting sort of number game: are we overestimating the epidemic or are we underestimating the epidemic? Well, I've seen wonderful--I don't even read the literature, the articles about them because it is somewhat irrelevant since we don't test and since we know that we are not very successful about changing behavior, which is mostly the work of the people in this room, of learning how to change the behavior, particularly of disempowered populations. We're relatively good at changing behavior of upwardly-mobile, successful people who have something to look forward to. We have a much harder time with people who don’t have too much hope and certainly don’t have many resources.

Enough jokes have been made about there are no running tracks in the poor sections of Harlem. We haven’t been able to change behavior of people who don’t have much to which to look forward. We have to figure out how we can find out the breadth and the scope of this epidemic. We have to figure out ways to encourage people to inform unknowing partners, and not put people at risk, and we have to do it in a way that is guaranteed not to penalize those people who have AIDS, and it is very hard. Traditional public health models, if they had been used on AIDS, would have had mandatory testing, mandatory partner notification, perhaps some isolation, perhaps the posting of names in public places—there’d been a lot of things that would have been done if this had been handled in the traditional public health mode. I’m not arguing for that because I think that the traditional public health mode was probably unnecessary half the time it was used for other diseases and epidemics. But there is the fact that this is a fatal disease that is communicable, and I don’t think that we are treating it seriously enough.

The previous speaker said, “This is the disease that could be wiped out, but it can’t be”. Well, of course it could. This disease could be ended when we stop passing it on, and we’re not taking that seriously enough, and I think it is not because we have an inability to discuss tough issues. I think it is because of our infatuation with a fix, and why would you spend all that time trying to prevent anyone else from passing on the disease ever again when we know that if we just put enough money into the laboratories there will be a fix, and everybody will be cured and we’ll get a vaccine and we’ll never have to worry about it again. Now that could happen tomorrow, and I assume it’s not going to happen for a long, long, long, long time, while the millions of more people become infected.

When I look at the growth of the epidemic, and the children, and the women, and the people of color particularly, we’re not doing one percent of what we need to do in a large scale. I think it’s because we don’t have appropriate vocabulary or forums for doing it. I think it may be because we don’t have a common culture and values, or that the values of our culture really aren’t for the preservation of life and the community and they’re for something else. That’s a bigger issue than I can discuss today, I think it’s a bigger one than just a public health agenda. But I think if we don’t figure out a way to identify and clarify core values that protect life and community while protecting dignity and safety of individuals then we’re actually going to see the disease grow and grow and grow, and then the us and them and the name-calling and the segregation and resegregation of people I think it will be growing and not be diminished.

David Satin:

I want to start out by taking issue with the Commissioner. That is not too large an issue to take up here. That is -- I suppose that is one way of putting the purpose of the Lindemann Memorial Lecture -- to look at values, to look at morality and ethics and how it informs what we do with one another, and how it underlies health-- mental health, physical health, and social policy. And maybe to reinject those values into a discussion of mental health and physical health. I think enough--too much -- discussion of health issues go on amorally, when you just look at figures or you organize protocols.

My favorite peeve these days is medical ethics, which was intended I think to ethicize medicine, and has ended up by medicalizing ethics. We don't add humanity to medicine through ethics, we technologize ethics by making them amoral, I think, and impersonal and "scientific". So, yes, I would like to hear a discussion of what are the values that should inform public policy and research and community activism, and how AIDS exemplifies a public issue, community issue, that needs to be addressed with some sense of values. I wonder if you want to talk with one another about the things that you have said, and how advocacy and research and public policy are or are not interrelating with one another, and what you need to hear from one another.

Discussion

Judith Kurland:

I think it's nice to open it up. I think we have very few occasions to do that, and very few forums in which really… people shy away from it whenever you mentionit, regardless of whether the people really care about the same issue or not. Often people who care about this issue are uncomfortable in discussing it.

I think one of the biggest issues that needs to be discussed is whether or not it is helpful or not to talk about these issues only in the context of AIDS or whether it ought to be brought…and I don't have the answer to that, but I go back and forth all the time, and I worry a lot about it in part because it is easy to see this as different and to treat it differently at every stage, whether it is community-based programs or research or medical care or in public health, and I actually worry then about sort of the resegregation of society. If we're going to have the breast cancer coalition fighting with the AIDS coalition fighting with the sickle cell coalition

when all of them should be together trying to get the money from the B-1 bomber, or truthfully getting money from the unnecessary and additional beds that are being built in Boston as we sit here. That are going to cost $1 billion out of health care for nothing, waste. I mean, we need, I think we need to have that kind of conversation. But I don't think it ought to be AIDS-specific or grouped.

Nicolás Parkhurst Caballeira:

You touch upon usually when you speak, and I always enjoy immensely listening to you talk about it, but I think that AIDS is for… the Achilles heel of medicine and the medical model. I think that it makes us face the fact that in this country and in most of the Eurocentric world, there is no health care, there is only disease care, and that unless we make the concerted effort to promote and protect health, and even to stop talking about prevention, which is already a negative concept, we are not going to be able to avoid this strife between people who are advocating for the specific needs of particular groups of people affected by one small disease entity, however large that may be.

So, I think we need to really look at our so-called health care delivery system and start putting the money where our mouths appear to be, and it should be in promoting health, and we have to make some very hard decisions that will be fought tooth and nail by the hospital industry, by the pharmaceutical industry and by all the disease industries, but that needs to be fought, and that is we need to be… tertiary care in this country to the point that we free the resources necessary to promote health, and that is going to be painful. All transitions are painful. But unless we do it, there is no solutionin sight.

Judith Kurland:

I agree with Nicolás, but I usually I'm on the left of the panel. I'd like to get back...I'd like to get back to the last...We're going to spend $1 billion more in Boston on adding unnecessary, wasteful, duplicative capacity to acute care hospitals. $1 billion. Which will come out of something, and you know, it'll come out of...it's opportunity cost for health promotion, for education, let's even get out of our field...education, housing. We're going to spend an additional $1 billion on top of the half a billion dollars that's already been committed. For what? For no good reason. We're doing it so that every tertiary care hospital can have everything. I mean a city that is so overbedded, we're going to have to poison people so we can fill the beds of the hospitals.

Nicolás Parkhurst Caballeira:

And we will.

Judith Kurland:

And we will. But we will because there won't be any money for environmental cleanup or for anything else. We're spending it. Recently the public health commission approved a bid, I apologize, no I don't apologize, I'm sorry if I hurt anybody's feelings...The Massachusetts General Hospital decided it needed one bed for bone marrow transplantation, because, and that kind of bone marrow transplantation research does not go on in either hospital. Massachusetts General Hospital is a Harvard teaching hospital. The determination of need says we need three bone marrow transplant beds in the city. We have ten. We need three, we have ten. But rather than have the researcher at Mass General go do his research at a fellow Harvard teaching hospital, if the research is worth doing, Mass General got its own bed.

Now what does it mean to get its own bed? If it just opened up the bed and got research money to do the research what is the big deal? No, of course it got its determination of need so that it could build for it. So it's going to come. We're all going to pay for it. And that money could have gone into immunization. I mean one of the great ironies is that everybody's working toward a vaccine for AIDS. We don't vaccinate for measles or mumps or diphtheria anymore. We've had epidemics of children all over this country, and yet everybody's working toward a vaccine for AIDS. I just find it wonderfully ironic.

But what is going on to stop this? The Boston Globe had an article about how wonderful it was that we have $1 billion worth of additional construction. Isn't that wonderful? Jobs. And we're all going to pay for it, and we're going to lose jobs in our industry because we're going to pay for it, but there isn't going to be the money to keep people healthy, to keep, prevent disease, I agree with Nicolás, we have to not always talk about prevention, but to prevent disease, to keep people healthy, to delead houses, so that hundreds of children are not ruined permanently. But there's always money for big institutions, for high-tech glitz, and for after-the-fact cures, and it's criminal.

Calvin Cohen:

The only thing that I would add to that is that in some ways we need to also then think about what is our role, each of us, in creating that, and certainly as someone who trained within those hospitals, I think everybody in some ways would share that we don't want to just fund the last hours and weeks and in fact year of life except for our family. We don't want to do this except for us. My mom, however, should get everything. And I think the problem or at least the conflict that we get into in medicine is that, I think there is a sense at least, that we need to shift our thinking about where are our priorities, and if in fact we do have to make these choices, and I'm not 100% sure again that these are the right ways to frame it, again, the choice between should we fund high-tech research or should we take that same money and do prevention, I again don't want to make it breast cancer or AIDS but research to find the cure and making sure that noone else gets infected, and from my perspective, that dichotomy of research or prevention is as unfair and as much a part of them doing it to us as these others, and again, both are needed. We all would like to make sure that everybody who is infected never has to get sick, but at the same time we want to make sure noone else need get infected, and those who…prevented. So I think both are priorities.

Nicolás Parkhurst Caballeira:

…worthwhile if we look at health more integrally. For example, it is very conservatively estimated that this country it costs $65 billion per year to try to remedy, and never remedy, the harm done by tobacco. Right? Four hundred thousand deaths and $65 billion are directly attributable to tobacco use in this country. And yet, I just received the Health News Report, where it says that the two leading candidates of our two only parties in this country favor allocating funds to export tobacco to other countries and promote the use of tobacco among people who have never used it before. In fact, the leading candidate of our prominent liberal party, the Democratic party, is saying that he supports any effort to promote American products overseas. The other one just spends the money.

So, I mean, here we have enormous amounts of money that could easily be shifted to something else because nobody is born with a need to smoke tobacco and if they were not cut up, rolled up and put in vending machines and other places nobody could really smoke them. So, I mean, why are we spending this money here? Where is the will to protect the health of the American people? And where are we making decisions that affect all of our health and all of our well-being and economic prosperity on the greed of a few major companies, such as Nabisco and Reynolds and all these things. I mean, we just spent I don't know how many millions of public money to put Noriega in jail, and if we analyze the harm that this man may have caused in his entire lifetime I am sure that any tobacco company in this country has done more harm in five minutes than this man could ever do if we left him alone for the rest of his life. And those companies we subsidize. Him, we invade the country and kill people to bring back and put him in jail.

Calvin Cohen:

Actually, him we subsidized.

Judith Kurland:

I agree with the last two comments, but I'd like if I may, I agree we need to do something about big issues, like tobacco and the power of American industry, and the rich get richer and control more, and I agree that we do need to have research and we do need to have community-based care, but I will now fall into the we have to address what we can handle, and what we control. And I would argue that we have a greater say and control over just the American medical care system. And I think it is fair to start there. We spend $800 billion on healthcare in this country, and 12-25% of that is wasteful. And I think it's fair that we should first start there and that we should first start here in this Commonwealth of Massachusetts, and I want to get back to the issue of what we're spending money on. Money is being cut for substance abuse, money is being cut really for AIDS, although it appears that money is going up, but when you fund some accounts more than you cut other accounts they tend to go down. Money appears to being spent on infant mortality but it's actually only gone for teenage pregnancy prevention. It's not going for other issues that have a greater effect on mortality, such as substance abuse. And we're adding $1 billion more of the cost to the system, and I have yet to have anybody dispute

me on the fact that it's unnecessary, and I think that we need to do something about that here.

I think it raises some of the issues that were previously raised, I mean, I advocate for the Canadian system, a single-payer system, when people say, people with good authority, say that $68 billion would be saved immediately on insurance costs alone. That's worth it to me--$68 billion --you could do a lot in the country on community-based health for $68 billion, and that's only the beginning. I mean, besides spending the money to keep people alive for the last year or the last day, every physician who practices in the hospital knows that too many endoscopies are done because they make money. We know that. We know in fact it even threatens peopleís health because often patients are told to come back too frequently, because previously underpaid physicians, primary care physicians, internists, can finally make money by doing procedures, and they do that. The cesarean rate in this country is still extraordinarily high. In this city, medical Mecca of the world, I mean, Boston City Hospital has and has had the lowest cesarean rate in the Commonwealth of Massachusetts for the past 20 years. And I would argue that we probably have a higher risk population than anybody else, so it's not that it can't be done, but we have very, very high cesarean rates. The Netherlands seems to be able to have the majority of women delivered by midwives at home. We could do things right now, and we don't do them. We don't do them at all, and instead we do look at the B-1 bomber, which is fair to do, but I think that we also ought to look at the kind of the medical-industrial complex that we, and this city survives on it, this is a serious issue for us. I mean what will happen if we actually got a rational, fair health care system would be we'd have the kind of dislocation people in Connecticut are having because of cutbacks in defense. But long-term, you know, it might actually be a good thing. I think we need to figure out ways to talk about it, and do something about it.

David Satin:

Let me encourage people in the audience to pitch in to the discussion

Participant:

About your last paragraph was filled with optimism about the application of the model of the observation database beyond the AIDS epidemic. I'm wondering, have you any reason to be this optimistic? Do you think that the consumer-driven research is possibly going to move beyond this epidemic into the larger community?

Calvin Cohen:

We have some information already…well, first of all, who has the motivation to want to take it into their own hands? Obviously, those who are feeling disenfranchised. Heart disease community, if we can use such a phrase, doesn't feel like they need it, because they're well-funded, there's lots of studies going on, but women with breast disease, for instance, or breast cancer or other manifestations of breast disease are finally saying, "Look, we're tired of being ignored, and if your research establishment is going to continue to ignore us then we have to do it ourselves, and we'll find those physicians and researchers who are interested in working with

us to get answers that we want now instead of waiting, because we're tired of waiting". And we do have evidence that that is starting to happen. It isn't necessarily making front-page news but there are certainly people in those activist groups who are going to the ACT UPs and saying, "How did you do this? Just who did you talk to and how did you get the FDA to respond to your needs this way?". And other groups are starting to at least get a sense, whether it’s cancer or for instance Altzheimers, there is a certainly a sense...For instance recently there was a drug being tested for Altzheimers called Takrin, and it showed some early promise. The FDA said, “Well, this is interesting, but nope, no approval yet, and no release, it’s too much, we have to just keep studying it”. And if this were AIDS, people would have said, “Well, you can keep studying it, but I want it now”. And interestingly, the outside community noticed that, but yet have not yet created the kind of pressure of going to the FDA and doing what AIDS activists did, you know, throwing blood, whether fake or real, on the doorsteps and getting the media to be there, and look at the national disgrace of making sure that you don’t have a drug available to you. And I think we do have at least an awareness that other communities have a sense as to what kinds of things they can do in order to start impacting on access to the things that matter in their own health. Is it happening in large-scale ways? No, I think itís just beginning. But I think it is beginning.

Participant:

But your vision of every patient’s experience being grist for the statistical mill by which the medical knowledge is enlarged touches a chord in my own memory. When I was an undergraduate medical student, a group of us met in Vanderbilt Hall in earnest planning on a number of occasions, because we knew that so much that was known in medicine was not solid knowledge, so much of it was just based on anecdote or the power of certain senior professors that this is the way it was done, and you go from Boston and you go to New York you’ll find that things are done differently in New York. You go to London, it’s done a lot differently. Well, we as medical students decided we were going to set up an organization, study all of medical care and find which of it, what of it was based on solid research and which of it isn’t. Well, of course that was too big for us, and as you know almost none of it is based on solid research. Almost all of it is based on all of this more ephemeral kinds of data, and the observational database--this could be applied to every patient on the planet. My, we could tell a lot. I mean, it would just... communities would drive their own care from their own experience, It would be most wonderful. We wouldn’t have to talk about B-1 bombers and extra hospitals. When you did this survey to find out what people wanted, you know, that wold come out of the observational database. It would become known what was needed. It’s such a powerful tool, and I wish you well in proselytizing it, and this is the AIDS as a model, but it is a model, and it is a lot of our lessons are applicable so I would hope that your last paragraph and the optimism is not misplaced.

Nicolás Parkhurst Caballeira:

I have an observation to make that I hope will not be taken in a wrong way, because I think itís an important observation. The very methodology of Western science, although it claims to be value-neutral, scientific, etcetera, is culture-bound. In fact I came across my first experience of this when I was discussing with some Indian colleagues, Indian from the country of India, and not American Indians. The whole question of the methodology of research, and we came across the phrase that we are so enamored of, the double-blind study as the pinnacle of scientific purity, and one of them looked at me and said, “Only in America would something that is double-blind be considered good. I mean, being blind is bad enough, being doubly-blind must not be a very good thing”. And actually, although it looks like a cynical comment, but it’s actually a very deep comment because in many medical traditions throughout the world, which are much older and actually have much more data accumulated over time, the idea, the fundamental observation has been that the intention, the healing intention, is at least as important as whatever physical components there may be in a drug or a treatment. And when you factor that out, you’re actually not testing reality, you’re testing something that will never, ever happen again out of your experimental design. So, I think a community-based research has to look very, very hard and very objectively at itís pretense of objectivity and scientific methodology and acknowledge that reality has nothing to do with that method and that the method actually may be driving us to the wrong conclusions.

Judith Kurland:

I think it’s also what gets...the information that gets disseminated is that which makes money. Obviously drug companies make money, they want you to know that their drug has an efficacy. There were a lot of drug studies done in nursing homes, and residents of nursing homes who had control over the location of furniture in their rooms, and the timing of activities that went on in the nursing home did better, and they did better in ways that could be quantified, besides qualified, fewer infections, fewer days when they were immobile, etcetera, etcetera, lots and lots of things. What happens to that?

I mean, a couple of nice studies, the group Living is for the Elderly Life, which is a nursing home-patient advocacy group, does some things with it, but you certainly don’t see anybody taking out full-page ads and any medical journals saying, “If you will only allow your patients to have more control over their lives they will do better medically, they will cost you less, they will live longer”. Now, if you take this pill, you can do better. And now that is a serious problem, in that the dissemination of a lot of information is left to the people who will benefit monetarily from that dissemination. Yes, there are some wonderful journals, but not to the same extent, I mean you donít have people going door-to-door selling moving furniture in nursing homes.

Participant:

You made a comment, though. I've been doing research into hospitals 100 years ago versus hospitals today. If you look at the function of what a hospital was for when it was first started, it was a place where homeless people went for care, because physicians went into the home to take care of people, whatever that meant. There's a lot less technology and biochemistry than we have today, but if people did not have homes to have care, they went to the hospital. And I could say there's a spiritual homelessness that has run rampant in our culture by the growth of all the beds in the hospitals, for so many people to have to come to a place that was for the homeless for care. There's so little care to be brought to the home. And for the mechanization, the scientification, biochemization of care into what's cut and dried and rationally linear, and out of the healing intention, which was probably a lot more predominant when my great-grandfather came over from Austria and wanted to go into medicine. So I think itís really important to see how much weíve changed in terms of value in 100 years or less.

Participant:

Information about hopeful research on individual or community behavior change, trying to get individuals or communities to change their sexual attitudes or appetites, or …power research and discussion of that we won't get very far changing their behavior…

Calvin Cohen:

Well, so far the one piece of evidence we have is at least looking at issues of teenage sexuality and pregnancy rates in teenagers. And, as you can imagine, there are many ways to approach that. There's the authoritarian "thou shalt not, just say no," and that's one school of thought. And that of course has kind of a religious element to it as well, you know, "thou shalt not," there's, you know, it's morally against, you should postpone it, and that's one approach. And then there's the alternative approaches, which is that everybody should have available all their, all the knowledge they need, but is that going to encourage people? Are people going to say, "If they teach me about condoms, then all of a sudden I'm going to notice my genitals and decide to use them. That I haven't thought of this before, but now that you mention condoms and birth control, I think I'll start using my genitals". And, you know, which is right, in fact what they have done is some research looking at the range of approaches, all the "thou shalt not" and making sure that what people heard was the horror stories, or what we did alternatively was in the other group we tell people, look, you can abstain, or you can have sex. Abstinence will clearly prevent all of this stuff. It will also prevent pregnancy, it will prevent sexually transmitted diseases, nothing like it, that's the best of which there is, but if you're gonna have sex, these are the issues, and these things are available to you.

To me in some ways the analogy that I like best is the seatbelt. You know, God didn't tell you to drive a car, it's kind of a risky thing to do, but if you're gonna drive, if you're gonna do something as foolish as get into a car, now, you could stay home and just walk and make phone calls. You won't get into a car accident that way. But if you're gonna be so stupid as to get into a car, and drive it, then you might want to wear a seatbelt. Now, it's not gonna guarantee that you won't ever get into a car accident and die from it, but it will minimize the chances. And so by using these methods you can minimize the risk of that high-risk activity. And so condoms might reduce the risk, and these might reduce the risk of pregnancy. And what we've learned from those studies is that in fact teenagers respond to being told what their options are and how to act on them. And that the "just say no" approach doesn't actually reduce sexual activity, and doesn't decrease birth rates in terms of pregnancy, but that letting people know that they have these options and they can act on them, but if they choose to act on them these are the ways they can act to minimize the risk of them, and they actually seem to work.

Judith Kurland:

I actually want to differ a little bit, because I think that education alone does not work on the teen pregnancy studies, and certainly not the use of condoms in the public schools around AIDS, that knowledge doesn't necessarily change behavior. What we...some of the studies that we've looked at and some of the work that we're doing ourselves is that knowledge has to really be translated into a sense of empowerment, and future, and it's not just knowing that if you don't have sex or if you use a condom or some other birth control method you won't get pregnant. It's rather, why is it worth your while not to get pregnant? And you know, obviously when there are mentoring programs, when there are job opportunities coupled with teen pregnancy, even after a birth, so that the act of one lack of success in preventing teen pregnancy, that there are opportunities presented to youngsters they tend to then change their behavior and delay the time between the next pregnancy, when there's actually something...I mean, even something simple, if you have a job or don't have a job, if you don't have a job, you're likely to have a second child faster than if you do have a job, it's a control study. But I think that's a very important issue, that, and I want to go back to with whom we've succeeded. We've succeeded in changing behavior, lowering smoking, lowering drinking of hard alcohol, changing exercise, getting people to exercise, cut down on red meat, from people that have a lot to look forward to. And we haven't changed it for people that don't have much to look forward to, or don't feel empowered. Even if they're hopeful, they don't feel that what they do is going to change their lives, and it's worked better with men than with women, it's worked better with whites than with blacks, worked better with rich than with poor, it all makes sense, it's so obvious it's almost frightening, and yet we haven't figured out that without changing our whole society so that everybody feels hope, which is really the right thing to do, but before we can do that, how do we change behavior? And I think it's really important to figure out how to change behavior because I'm not that optimistic we're going to change the whole society in time to save anybody.

Nicolás Parkhurst Caballeira:

I think that you're pointing to a fact that should be obvious but people refuse to see it, is that the intervention once again I go back to the matrix that I put up earlier, we're only looking at one impact level, the individual, most of the time, and we're trying to change behavior by convincing this individual that this is better. If there is no normative risk reduction, and by that I mean social enforcement and pressure, and if there's no environmental changes that favor that, let's use the seatbelt, you cannot use the seatbelt unless the seatbelt exists, right? I mean you may have all the knowledge, you may even have pressure from your peers to use a seatbelt, but if the car that you're driving doesn't have one, you can't tie yourself up.

The same thing happens with every single behavior--there are things that you need in order to act. If the things are not there, you cannot act. That's why richer people, whiter people, males tend to have better health outcomes and change their behavior because they have the environmental resources, and they also have the normative risk reduction and the social enforcement that comes from their peers. And all our interventions have to, from the very beginning, address all three impact levels in order to be successful.

Calvin Cohen:

Well, we also have to tell the truth, which is to say that you can't just say, "No, don't do it, because that's the only way," because that doesn't work. It's not enough. We have to tell the truth and say, "in fact, all of these behaviors do exist, and that whether I tell you or not, you're gonna find out". And I think that part of what we need to do is really learn how to tell the truth about people's behavior options.

Participant:

Would you please speak to the community-based efforts that are underway or collaboratives that are having a constructive impact on a community level? Political system and the institutionalized roadblocks... Is there any hope?

Calvin Cohen:

It depends if Steven King or Steven Spielberg is writing the novel. I don't know who's writing this novel.

Judith Kurland:

Well, can I mention, and forgive me because it's mine, and I apologize, but in Boston we are starting something called Healthy Boston, which is a community-building, community-empowerment model of trying to bring together health, human services, education, housing and economic development on a community level. And I don't know if it's gonna work, and it's not original, so when I say it's mine, it's not original, I mean you have model cities, we've had these attempts before. The only thing that's different is we're trying to do it citywide. But the thing that makes me hopeful about it is two things, or several I guess.

One is: we are a city of phenomenal resources and very poor people and that's because the resources are controlled by institutions and not controlled by people, and this is not different from medical care. I mean, you have billion-dollar academic medical centers and you can't get vaccinations for kids. We actually do that well in Boston, but most cities they don't do that well. So I'm hopeful because there actually are lots of resources, not enough and can get them away from those that have and give some control over them so that those that don't have control is going to be hard but it's a very rich city in a lot of ways.

Secondly, almost everybody from every profession knows that he or she can't do his job or her job because it actually comes out of something else. I know, I'm the Commissioner of Public Health, I know that if you don't delead houses, I'm gonna have lead-poisoned children, and, yeah... is one. They're gonna be lead poisoned and maybe ruined for life. And that is, and I'm not in the business of lead removal, although that should be a whole housing and banking issue. I know that studies all across the world have shown that the health status of a child is directly related to the literacy rate of the mother. I know that. I'm not the education commissioner, I don't have a lot of literacy programs, although we have one, but I know that if people were better educated they would be healthier. But so does the Superintendent. The Superintendent of Schools knows that if the child comes to school well-nourished and healthy, that child is going to learn. And the Police Superintendent knows that he could have a policeman on every street and there would still be violence. So, I think all the professionals are finally saying, "I can't do this job by myself, and I don't want to do your job," which is what they first said. I'll do the other person's job--give me the resources. That we really have to bring things together. Healthy Boston is now in 16 communities around the city, and it's just beginning. Sixteen community coalitions have formed, the requirements of their forming is that they have to be very inclusive, and we're going to make them be more inclusive, that they have to include ordinary people, residents, not just institutions, because of what I said, you know some group gets in power, they become the establishment right away, and they forget the next group in. So I think that there's an opportunity in this city.

I would also argue, and I believe this strongly, that Boston is small enough to do things. It's only 600,000 people. Our problem is that we have so many institutions and interests. We have 16 teaching hospitals, 24 neighborhood health centers, 3 medical schools, 2 schools of public health, I don't know how many social service agencies. We are too rich in institutions and almost too experienced, I think, in having advocates get control of a very, very small piece. I think Kansas, although I've only been to Kansas once in my life, but it is small --600,000 people. We ought to be able to do something. We pretend we're New York and L.A. and Chicago. We're 600,000 people—we're a tiny little city. So I think Healthy Boston is an opportunity. I also think one of the opportunities is that national foundations, for the first time, are saying, "We keep funding these wonderful, little, precious examples of how to do something, and nothing ever changes, and things keep getting worse. We want there to be collaboration," and the nice thing is that national foundations, given that they give a fraction of the money the government gives, still have a major influence, I think, in new initiatives. I think the last ones to come to the table are going to be the government. And I work for government, I believe in the public sector, but I think that it's going to be easier to get the city, and then next easiest to get the state, and it's going to be the federal government that's going to be hard to get to change its ways, but I think there's some initiatives.

David Satin:

Let me not stop the discussion, but at least turn it into a more informal affair, and bring the lecture to a close. I think we've accomplished our purpose, and talked about community-focused health care, and we've used AIDS as an example of community focus on health care and welfare. I'm reminded that at one time there was an organization called The Department of Health, Education and Welfare, when they did bring all these things together. For some reason they were separated out again and redirected. I think we have begun to talk about some of the values. We've begun to hint at some of the values that ought to underlie what we're doing, and underlie community and social function, including AIDS, but including other things, too, the things that you all have been talking about is looking at community, looking at people, looking at residents, the citizens, as the unit to be addressed, and looking at organization and empowerment, and creativity about understanding problems, and bringing resources to bear on problems, and getting around ossified and obstructionist and perhaps no longer efficacious institutions and practices which block and don't facilitate the way of doing things.

It’s interesting to hear that government is going to be the last to deal with, going to be the last institution to deal with the peopleís needs, because supposedly government was set up to meet people’s needs, that is the justification of government. But also remember we elect the government. The elections are not illegitimate, they are not stolen in more than the usual sense that elections are biased. We are getting what we elected, and maybe we have to address the other needs, the other motivations that get us the government, and get us the practices that we now have to contend with.

Well, I think we have also fulfilled the purpose of the Lindemann Memorial Lecture, which is to address important issues of public concern, and of social impact, and address them with an eye to the values and the importance and the community and social aspects of them. I want to thank the speakers and the audience for addressing this topic, and for bringing us the enlightenment and the exploration that is in the best tradition of the Lindemann lectures, and I will invite you all to participate in the 16th Annual Lindemann Memorial Lecture in April of 1993. Thank you.