

**Inaugural Health Education Research Disparities Summit:
Health Disparities and Social Inequities:
Plenary III: Effective Research Dissemination Through
Evaluation and Community Involvement
August 9, 2005**

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COLLINS AIRHIHENUWA, Ph.D., M.P.H.: Good morning, and welcome to the second day of our summit. I want to thank all of you for your participation, involvement, and commitment yesterday. I think we had a quite engaging conversation/discussion and would like to continue this morning with the same tempo and spirit as we ended with yesterday. I wanted to say at the outset as a reminder, in terms of what we're focusing on for this summit. The focus of this summit is really on racial and ethnic health disparity, even as we understand that disparity goes beyond that. In the spirit of what Shiriki Kumanyika indicated yesterday, starting with what you have to leverage, or the possibility in terms of focusing, looking at what we have with clinical care, access to health as a focus of health disparity and then trying to move into what we haven't been doing. We see this as an opportunity, a beginning, and of course, as you all know, SOPHE has always been committed to diversity in its broadest form, and admitting disparity beyond racial and ethnic, but I just wanted to remind us too, so that we are all on the same page that this is the focus. The recommendation that comes out will of course allow us to also move into areas that we are not currently specifically addressing at this minute. To that extent, I would strongly encourage you to please not wait until the end

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of the day to complete your evaluation form, and share with us your ideas. You've had some wonderful ideas all through yesterday and we encourage you to please continue to complete this evaluation form and leave them on the registration desk. Don't wait to the end to do that.

So with that, we'll move into the Plenary III, which is the focus this morning, and I will welcome the moderator. We are very fortunate to have Dr. Clanton, who is the Deputy Director of Cancer Care Delivery Services at the National Cancer Institute to lead the plenary this morning. Dr. Clanton. [Applause]

MARK CLANTON, M.D.: Thank you. It's good to see you all here. I don't know how many people are staying at the hotel, but for those of you who had to come in from somewhere else here, your hair is probably a little moist and your glasses still may have fogged up a little bit, but we're glad to have you here today. [Laughter] I'm glad to be here. I just going to make a couple of remarks and then we're going to get to a more interesting part of the program.

At every opportunity, it doesn't matter whether it's a meeting on advanced imaging in cancer or a meeting that is coming up fairly soon in terms of AIDS-related malignancies, I take an opportunity to make a couple of statements about the problem of cancer, the problem of quality, and certainly that

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problem of disparities as it relates to my particular disease. It is fairly clear that the scientist's knife cuts into the problem of disparities, the scientist's knife cuts into the problem of knowledge or lack of knowledge around cancer in particular in the same way - that is, let's break it apart, let's see what the pieces look like and let's see what the problems are in those separate pieces and let's go and fix those problems. Cancer is unfortunately way too complex to apply sort of the traditional analytical research tool, and it doesn't matter whether we're talking about genes or protein patterns that connect with disease, targeted drugs, or the sociologic aspects of the disease. In fact, it really may be an inappropriate way to deal with cancer, by breaking it up and really looking at the pieces. In the delivery system, we're thinking more about applying complexity theory and chaos theory because those constructs allow you to look at multiple factors that affect care. Chaos theory allows you to look at multiple domains that really impact not just delivery, but also various aspects of healthcare. So, then the question is, what is the problem with disparities in healthcare or cancer? There will be those who will say it is lack of money, or lack of coverage, lack of insurance, or even managed care itself. There would be those who say we don't know enough in order to treat people appropriately. Still others will say the doctors know what they

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need to know, but they just don't do a good job in terms of delivering what we know. And still others, some of them at CDC and NCI will say we have a huge problem in terms of moving research and the knowledge it produces into practice; that is, translating research into practice. We can't do that well enough. Well, as it relates to the delivery system and as it relates to the total impact of cancer on public health, my answer is, all of those things are involved, and all of those things need to be addressed, and in some cases, addressed simultaneously. So certainly what you're doing here through this research symposium is important. If we don't understand how to disseminate the knowledge and get it into practice, if we don't understand how to translate the knowledge so people can use it or at least know what they should be getting, then in fact, all of the scientific and genetic and proteomic [misspelled?] discoveries that we will make and will be making in the next ten years really will not reach all of us and affect all of us and therefore the public health impact of the disease will not be changed. So, I would simply ask you to think of cancer, and think of delivering care as it relates to cancer or any other condition as a systems problem. Certainly you will have your part, you will contribute to your knowledge, but always understand that the biggest impact on changing the effect of this or any other disease will be to figure out how

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the parts connect, and how can we optimize all those parts so that better care is delivered?

So, there you have my theory on systems, and how we begin to think about systems, certainly at NCI. And now onto the more interesting part of the program. What I'll do is to read the quick bio for each speaker right before they speak, and we have a thirty minute, ten, ten, ten minute distribution. We'll work our way through those, the [Inaudible] session and then the respondent. And then with the time remaining we'll take questions from the audience. I've been asked to remind you to do your evaluations. I'm not sure if you have paper evaluations. I understand it's a high-tech meeting with electronic stuff [Laughter]. However you might do those evaluations, please do those. And now I can get my parking validated because I've [Inaudible].

Our plenary speaker and our first speaker is Mindy Thompson Fullilove. Mindy is a research psychiatrist at New York State Psychiatric Institute and a professor of Clinical Psychiatry and Public Health and Columbia University. She is a board certified psychiatrist, having received her training at New York Hospital, West Chester Division, and Montefiore Hospital. She has conducted research on AIDS and other epidemics in poor communities with a special interest in the relationship between the collapse of communities and decline in

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health. For her research she has published *Roots Shock: How Tearing Up City Neighborhoods Hurts America and What We Can Do About It*, and *the House of Joshua: Meditations on Family and Peace*, as well as numerous articles, books, chapters and monographs. She was named a National Associate by the National Academy of Science in 2003, honored as one of the best doctors in New York and awarded two honorary degrees. Help me to welcome Dr. Fullilove [Applause].

MINDY THOMPSON FULLILOVE, M.D.: So, I'm gonna talk about dissemination of research findings, and I have very little left to say. Dr. Clanton said it all, so, now I'm done.

I'd basically like to elaborate on what he said and argue that obviously we have large problems with dissemination. The piece I'd like to add is that I think there are two interesting things in dissemination. Some of the times, what we're disseminating is what I'm going to call things that are obvious about dissemination. You have to let people know the data, you have to use many channels of communication, use respected voices. You have to repeat the message. As Dr. Clanton says, everywhere I go, I say this over and over again. That's kind of the obvious. I think those things are all true and important and we can't escape them, and when we talk about dissemination, we talk about this clump of it all the time and all the pieces that go with that - how we find respected

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voices, blah, blah, blah. So, there's much elaboration of all of those ideas.

One of my experiences in the elaboration of this was through the Task Force on Community Preventive Services. Many of you are here from the CDC, so you know about the Task Force. I've had that honor of serving on the Task Force for eight years. It was a really great experience. The Task Force, in case there's anybody that doesn't know, was set up to do evidence-based reviews of public health practice and was started in 1996. It just published its first book, The Guide to Community Prevention Services. The way the group operates, the first thing we did was select topics, which became chapters. Each of those topics then had a committee that included people from the Task Force and the CDC, but around that committee was immediately engaged a very large number of other people who served as consultants, and these are the people from the interest groups for that topic—researchers who were concerned about that topic, people in all of the various government agencies that were concerned about that topic—so that immediately a group of about 40 or 50 people with all their different networks was engaged on each of these chapters. I served on the chapter on the sociocultural environment, and a vast number of people who were interested in those kinds of issues of housing and education, cultural appropriateness of

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services were involved in helping to develop the chapter. So, from the first instant, the list was actually decided by the Task Force, but from there on, the work was conducted by very large groups of people who were well connected. And at each step, as the thing went forward, as there would be a draft of the chapter, it would go out for public review, very, very widely. So, creating some buy-in and creating awareness of the Guide started from the very first day and it was embedded into the organization of the Guide. This has become and even more complicated and carefully attended to work of the Task Force as there have been more and more findings. They paid a lot of attention to the occasions on which the findings from the guide, the recommendations seemed to actually be pushing policy - getting the findings to be incorporated into the CDC requests for proposals, for example. If you want to work in this area, work on something that hasn't been tackled and look at the Guide to see where there's a lack of evidence. Don't do the stuff that we already have a hundred steps, do something else.

So, this creation of partnerships and then the creation of tools for outreach, going out and doing focus groups with people to say, "How should we do outreach in this area?" Then going back and going through key state level and county level organizations was a very dedicated work, so there's a whole group at the CDC that just works on disseminating the findings

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of the Guide. It was an enormous task so we might just take a test: How many people have heard of The Guide to Community Preventive Services prior to my speaking here? So they did a pretty good job.

If you think about it, in 1996, nobody had heard of the Guide because it didn't exist. So to get to the point where a slightly random group of people have all heard of it—some of you may have even picked it up or used it on occasion—is an accomplishment. This is sort of in the realm of what is called obvious. Just to be clear, what I mean about this obvious/not-so-obvious, most of what the Guide is telling us how to do is taking research that's already been published looking at it, trying to see if the weight of the evidence supports saying, "This is a good thing to do," and then telling people the weight of the evidence is enough to really support this. So, obviously, there's already been interest in the questions if there have already been studies that have been funded by agencies, so this is almost a secondary process. So we say to people, there is enormous weighty evidence that says, if you send postcard reminders, people are more likely to show up and get their vaccines. It is good to know that if you send a postcard reminder people will show up and get a vaccine. My dentist uses postcard reminders. You may get postcard reminders from various people in your life.

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But this is not earth-shattering news. What I want to talk about is, sometimes you actually have earth-shattering news, or at least we hope to, right? That's our dream. You know, Galileo and Marie Curie, they had earth-shattering news [Laughter]. Sometimes we do research that actually challenges the known truth, right? And sometimes research actually demands a consciousness, like, in order for you to understand what I'm about to say, you would have to have a consciousness that you actually don't have. And here I speak as a psychiatrist. How do we understand this? A great deal of what cognitive science has helped us to understand is that people get what they already have in their head. Right? We work from Schemas that are in our minds, so we hear what we think we hear, we see what we think we see. If we don't have it in our heads, we can't see it, we can't hear it, we can't feel it, we can't experience it, we can't understand it, can't get it. Well, what do you do if you have to tell a truth for which there is no existing consciousness? What if you were Albert Einstein and you discovered the Theory of Relativity? There are five guys who get what you're trying to say [Laughter]. And your wife, who might have told you. I think Al knew it. What if you're Galileo and you're saying, "It's not true that the Sun rotates around the Earth. The Earth, I hate to tell you this, rotates around the Sun." And they say, "Recant or we

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shall burn you." I mean, I'm sure nobody in this room has ever been threatened at being burned at the stake, but that exists as a possibility, and lots of people in this room are doing community-based [Inaudible] research for which they may never get tenure or take on other challenges, and have had to confront the status quo. These are very difficult situations when you have to tell people something for which they have no consciousness, and which may be very frightening to them. This is an important issue, because we live in a country where the President has said it's a good idea to teach Creative Design alongside Evolution. This is not a country of scientifically literate people, so wherever the cutting edge is, the mass of the population is not even there. There are tons of things that you could say that people have not got the cognitive stuff to hear. How do you disseminate in that circumstance? What do you do so that you don't get burned at the stake? I give a list of some of the things for which there is not appropriate consciousness. Some of the examples of things for which there is not appropriate consciousness in the general public when people are working on disseminating these problems are facing a tough sell. I mean, physics and math, nobody even learns any physics and math in the United States, so when mathematicians publish articles nobody even knows what they're talking about. I work closely with Roderick Wallace who's a physicist, who has

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a lot of math in his articles, and everybody simply pales.

I want to talk about some of the things that we've been through at the Community Research Group where in just watching what's been going on, and as things have come up, what they've hit, where it's been easy and where it hasn't. Our group has been doing AIDS research, and members of our group have been doing AIDS research since 1986, and as we all know, the AIDS epidemic was redlined. By that I mean that it was understood to be an epidemic among a disadvantaged or despised, highly stigmatized set of people of various different groups, but the set of people with AIDS were highly stigmatized. And therefore, nobody needed to worry about it or think about it, and pushed it out of their consciousness. So we've spent years in the struggle to help people understand that AIDS is here, part of our daily lives. We've been thinking about it. We've worked a great deal on problems of the black church and its complete refusal to bring AIDS into the discourse of the church.

We thought AIDS was bad, but then we started watching crack, and crack is much more redline than AIDS. We did an examination of federal funding for crack, and there's basically no funding ever for crack, which is astounding. Some of you are old enough to be my age and therefore to have been in neighborhoods as crack was coming through and to have witnessed

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the utter devastation, the horror, how many lives this ruined. Now we're seeing the second-generation effects of the kids whose families were broken up. That was just an extraordinary catastrophe for which there was no really research done because it was redlined. We worked very hard to try to raise consciousness around this, really to no avail.

By contrast there was a multi-drug-resistant tuberculosis epidemic. Again, the obvious: We get how tuberculosis is contagious. We are afraid of that, right? This is known. The rapid and immediate response to that was just astounding. It's the only epidemic that I've watched which has gotten the full support of every level of government immediately and which was contained, basically eliminating it as a threat. But I think eliminated as a threat is too strong, but the full support of every level of government immediately, on the recognition of the epidemic; this is the only case that I've seen.

And then greatly troubling to me has been the number of times that I've heard the phrase, "You can't change structure," while the structure has been changing constantly. Why do people say we can't change structure when every day the New York Times the way New York's structure is changing. The New York Times is telling us that a few of the rich are getting all of the money and the rest of us are being left poor. That's a

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change in structure. Structure is changing. Why can't I be part of it? What's the message here? Why can't it be part of our discourse in public health? It's certainly going to affect health of the American population. Why can't it be talked about? And why can't we understand that structure does change? What's the taboo here? This is the most important taboo that we all work with in the professional circles that we inhabit. It's not just a taboo, it's a lock, or it's a rule. I can't change structure. Other people can't change structure. You can't change structure. It's a very important concept, but everywhere you go, as soon as you start to talk about structural issues, "You can't change structure. We'll never end poverty. Why is that true? Why end poverty? Or we'll never eliminate racism, or it'll be a long time. It might be; it might be tomorrow. The things that change really quickly teach us that change has long phases and short phases, so how long something's going to take is actually something we don't know. There was a belief in New York City that tall buildings stand up. This belief changed in a 45-minute period, and you all know what 45-minute period that was. Very fast, the belief was wiped out. Now everybody in New York believes tall buildings will stay up most of the time. That's a big shift. How do you feel if you're a little kid and your mom goes to work in a tall building? You don't want her to work there

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anymore, because you know that tall buildings don't stay up all the time, only some do. So, things can change incredibly fast. Lyndon Johnson signed a law and all the hospitals in the United States were desegregated, so in one minute we went from segregated hospitals to desegregated hospitals—one minute.

Important things. So I'm going to just delve into some of the experiences we had when introducing the concept of Root Shock. Out of our studies of AIDS, and especially influenced by the work of Dr. Wallace, we have examined in great detail the ways in which the AIDS epidemic has been fueled by population displacements. Dr. Wallace talks about the displacement of poor minority people in the South Bronx in his classic paper on synergism of place, but many other populations have also had augmentation of the epidemic because of population displacement, and it obvious that if you mix populations, you add a new element into the spread of disease. And if you mix populations enough, you can really help an epidemic get going. Population displacement is not enough, but it's useful. That combined with a few other things, you will get the most fabulous AIDS epidemic under those conditions. The other thing you have to have is nooks for exogamous exchange of bodily fluids. So there are many forms of displacement and not all related to AIDS, which as we started to think about displacement, we realized what a massive problem

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this is around the world, and that there are important psychiatric effects of displacement. This is our contribution to psychiatric theory, that we have important attachments to places and when people are displaced these psychological connections and psychological work that is done with regard to place is ruptured, and people are left having to reformulate those connections. They have to fall in love with a new place and become oriented to a new place. They have to do the work of building a new identity from a new place. It's not always able to repair these damages, and in the absence of repair we get alienation and other ills. Much of the young terrorists growing up in Britain fall into the category of these kinds of ruptures and lack of good repair. So the populations that have immigrated but not really felt at home in the new place, and to have alienation and rage, which then becomes a tool for extremists to use. So, this has important worldwide consequences if we don't do this work and paying attention to displacement is important.

These two are sort of the faces of displacement. The first is a woman, obviously an etching [Inaudible] back in the 1860s when it was Baron Haussmann who was ripping up the streets of Paris and throwing the poor out of the center of the city to the edges of the city. The second is a photograph taken in the 1950s of a woman who is being displaced from a building that's

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going to be made into a federal housing project in Pittsburgh, and she's arguing with the movers who are planning to take her out of her house. The stress is related to the kind of ripping away of context, and that context is not simply something that's outside of us but that enters us through these important psychological processes. Through the process of moving in space and living in space and of viewing it with meaning, it enters into our bodies and our consciousness, and when it's ripped away, especially very quickly, it's a devastating and shocking experience. This is the Hill District in Pittsburgh, and these are the plans that were created by the Urban Renewal Authority, which was headed by a very large group of very important, powerful white industrials who decided to bulldoze this black neighborhood and create highways that would make it difficult to get from the rest of the black neighborhood of the Hill District downtown, and also to put in that round circle an entertainment facility, which is called the Civic Arena. And this is what that looked like. Karl Jung has done a lot of theorizing about flying saucers [Laughter] and he said that people in many cultures see flying saucers and that the sense of something that comes from outer space is deep in our psyche. Anyway, people are afraid of flying saucers. So not only did they put in highways and a vast track of empty land which is still reasonably empty today, they also put in a flying saucer

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so that the number of real and symbolic statements that black people are not supposed to go downtown is enormous. This kind of spatial marginalization was one of the outcomes of urban renewal, not just in Pittsburgh, but in many, many American cities. So, creating a break, something that was previously continuous became two separate places, and never the twain shall meet. But the Kerner Report was to say after the riots in 1967 that "America is in danger of becoming two nations, separate but unequal," and this is part of the creation of those two nations. When we think about health disparities, we are thinking about what the Kerner Report said was coming and what all the consequences of that were. So that is what we call Root Shock, this violent stripping away of context, which leaves people shocked, and we take the term from gardening. Gardeners use it to talk about the state of a plant goes into if it's been brutally ripped out of the ground. Even if it's being transplanted very carefully, roots can go in to shock and the plant may die because in the process of transplantation if you don't get enough of the root, if you don't transplant it carefully, if you don't put the roots in properly, if you don't tamp down the soil and give it the right amount of water, the plant is very vulnerable. Well we argue that people, especially those who are moved against their will, but even more broadly than that, also go into a state of shock, having

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lost the connections to their place. Now, some of you may think, "That's really obvious, I get that," and some of you may be saying, "That's really a stupid idea." At any rate, that's the idea that we wanted to sell, and some places where we've been, some people say, "I really get that," and some places people have said, "People move all the time. Those black people probably wanted to move because they had bad housing, so why would they have root shock?" So, not everybody buys into this idea that we're putting out, nor is it obvious, and we find it's not obvious because people often talk to us about the fact that Americans move, so being forced to move is just another kind of move. "I've moved. I've been fine. I got a better house; I'm happy, look at me. So other people being forced to move, must be the same thing," and since Americans aren't very scientifically literate, they give a logical argument, "As evidence, I've moved and I'm fine, therefore, they're fine." This is a very good American argument. And the second is, "Well their houses were run down. Why wouldn't they want a better house? I want a better house. So they're fine." Furthermore, that you did something in geography, that you moved somebody to someplace else, Americans don't get taught any geography. Many American universities, like Columbia University, have eliminated their departments of geography. There's very minimal training in either geography or urban

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studies. And then finally, people in power like to be able to displace people—and they particularly choose the weak because it causes less fuss—because then they can do other things with the land, and there are plenty of other things people want to do with the land. Among other things, developers have found this to be a great way to get to do their next project. As cities get built out, where do you build your next building? Well, you have to go back into the built part and erase something. How do you erase something where people own it that get in the way? You just go to the government and say, “I’d like that, please,” and then they [Inaudible] for you and give it to you. And the furor that’s around eminent domain has to do with the fact that this is a very convenient way for developers to make a lot of money on into the future.

Now when I say this is so, the dissemination of this new idea immediately runs into a wall, and the wall is that to the extent that the people in power really like to be able to move people, they don’t particularly want to talk about the downside of this. There is no documentation that was done about the African-American experience of urban renewal, right? “What did that feel like to you as an African American who lost your neighborhood?” This was not done until I would do Root Shock, which is 40 years later, 50 years later, in some cases. But it’s a deliberate choice not to document the experience.

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"Everything's fine. It's just like moving. We do it all the time. And it makes the city pretty. Why wouldn't we want to do that?" There's a brilliant thing on eminent domain on CNN, a little clip. I think it's in the financial news section, talking about some old people who have a little house by the beach and the city wants to put in condos. So they talked to some women on the beach, and they said, "Well, you know, they've just got to move because it's progress and it's just gonna look better." And they're in front of some of the condos. They're like, "Look how beautiful this is."

Meanwhile, the people have this cute little house, these old people with this cute, little, nice house that they've paid off, and they're like, "We've paid off our house. Why do we have to move?" The point that I want to make here is that if you're trying to disseminate an idea that runs counter to the policy of the political powers that be, you have an uphill struggle. Just as the Catholic Church didn't want Galileo to say that the Sun is not rotating around the Earth, but the Earth is rotating around the Sun, they don't want you to say that eminent domain, or forced displacement is a bad thing. In Zimbabwe, they're forcing displacement of hundreds of thousands of people. Obviously the power structure doesn't want you to say it's bad. "Well, they'll go live in the country. It'll be fine. They'll have a new house." No.

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So the question is, we've got to push this idea up a hill. What do we do? Part of it is that, we believe, that you have to create in a way, a consciousness that can receive the idea, so people think, "Everybody moves; it's no big deal." Then the first thing you have to teach people is, "Well actually, think about your connections to your neighborhood. Think about your neighborhood. What has your neighborhood given you?" You have to go back and step and say, "Neighborhoods are actually important. Do you like the shoemaker that you go to all the time in your neighborhood? How about the dry cleaner? How about the wine merchant who always knows what bottle you need?" Neighborhoods are important. Your neighbor who brings you soup. You know especially the nerds who say, "Well, you know, all my best friends are on the Internet." But they can't bring you soup when you're sick [Laughter]! So, we have to teach people that neighborhoods are important. Borrowing from the Task Force, we have to link to groups that are concerned about displacement and we have to link to scientists that are concerned about structure.

Mark just gave me that fatal [shows five fingers], so— what I want to say is that teaching new ideas we have the usual tools, articles, books and talks, all of which we've done, but we've also been using some new tools. The first is that we

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made a movie, called "Urban Renewals: People Removal," which we are proud to say won Best Short Documentary and the Trenton Film Festival, and we're making a second movie, "Master of Space, the Urbanism of [Inaudible]". We also take people on walks when we go to cities, to look at the neighborhoods. We have developed a track and M.P.H. program at Columbia called Urbanism and the Built Environment. We have developed an academy, a research group, and we do international exchange. So this is us going on a city walk in Harlem with colleagues and local people. To the left is my husband Bob talking to an area resident, who, as all area residents, just told us what the whole real story was. As soon as you go walking around, people start to tell you what's going on, and it's a great experience, so we do a lot of city walks. Another way in which we've put these ideas into practice was through work after the collapse of the World Trade Centers called "NYC Recovers, Year of Recovery." At the end of the Year of Recovery, we took our logo, which was just the buildings with a heart, and everybody colored on it, which in a way made manifest, how does a city recover? It was a way of saying, "Okay, we've been together for a year, we've done all this work. What did we do? Here's what we did." And you see how the city is repaired? If you look at the logo, you see that none of the buildings touch the ground, and if you see how everybody colored it in, every

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building is now connected to the ground. This is from walking in Greenbush, which is a neighborhood in Madison, Wisconsin. Greenbush was destroyed by urban renewal, and this is a monument. It happened to be cold that day, but the monument was warmed by the sun, and so all the kids were hugging it and saying, "It's warm!" You can see the words, which are the words of different people in the neighborhood, remembering their neighborhood. This is a visit to East Baltimore, a neighborhood that's about to be bulldozed by Johns Hopkins to build a biotech center. Now, we read this in America as, you know, those are terrible buildings; who wouldn't want to leave home? Who wouldn't want to move out of that neighborhood? And then the teaching is yeah, but what about the kids? What about the kids that are having fun in the sprinkler? So as soon as you go into a place like that, you encounter the living tissue, and the kids have a message. This is Tiffany, who is 13, and she said it was really great to have her picture taken on her birthday. It doesn't take much to encounter the living tissue in a neighborhood that we read. Now, in contrast, on our recent trip to France, we were walking around a charming old city part of the city of [Inaudible], which is nestled between the Mediterranean and the Pyrenees. It was an ancient capital of Catalonia, and it was extremely beautiful. You can come with me next year, if you like. And we're going on a tour of

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what looks to us like romantic old France, and so in its essence, it's the opposite of coding. In all the romance, where's the pain? It was just beautiful, and her was this little fish store. But here's the pain. All of those people live in a house that's three stories tall and about ten feet wide. All of those people have families, so intense overcrowding, worn out buildings, and then all the challenges of how do you upgrade a historic neighborhood of that sort?

So, these are some of the things that we're doing to try to teach about the concept of Root Shock. We've found it to be very challenging to teach a not-so-obvious concept. We think it's taken us an enormous amount of new tools to try to get through. We do have some indicators that people are picking up our message. For example, Root Shock was used in a number of [Inaudible] briefs for the suits against eminent domain used before the Supreme Court, including the brief by the NAACP and others. So people know about the work, are thinking about it, and are getting in touch with us. Of course, it's very easy to connect to people who are experiencing Root Shock; it's getting out beyond that. But I'm pleased that I've been invited to speak to the realtors, a developers' organization in New Jersey who are thinking about eminent domain and have invited me to talk about the failures of past policies.

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So, Mark says it's time and I have my last sentence. I think our greatest challenge as public health educators is that we have to teach the cutting edge ideas and we have to teach our students how to be bold in the face of challenges to the status quo. Dissemination is easy if it's postcard reminders, we'll get people in for their vaccine, but it is not easy if you have to tell them that the Earth rotates around the Sun, and sometimes that's the truth that we have to give out. Thanks [Applause].

MARK CLANTON, M.D.: I have no doubt that there are a million and two questions that you'd like to ask right now. Forgive us. What we'll do is we'll work our way through our panel and then we'll have an opportunity to ask any questions later.

The next presentation is on successful dissemination, and our presenter is Leandris Liburd. Leandris Liburd is Branch Chief of the Community Health and Program Services at the CDC, the National Center for Chronic Disease Prevention and Health Promotion, Division of Adult and Community Health. Prior to that she spent 12 year in CDC's Division of Diabetes Translation where she provided national leadership in developing community models for diabetes prevention and control programs for racial and ethnic communities in the continental United States, Pacific Rim, US/Mexico border and Southwest

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American Indian tribes. Miss Liburd holds a Bachelor of Arts degree from the University of Michigan at Ann Arbor, a Master of Public Health and Health Education from the University of North Carolina at Chapel Hill, and a Master of Arts in Cultural Anthropology from Emory University. She is a doctoral candidate in Medical Anthropology at the Emory University, where her where her principal research focus focuses on understanding intersections of race, class and gender in chronic disease risk, management and prevention. Please help me welcome her [Applause].

LEANDRIS LIBURD, M.P.H.: Good morning. Can you all hear me? Do I need to pull the microphone closer? Can you hear me now? Thank you. First of all, I want to congratulate SOPHE for the summit. It has been a wonderful, very enlightening experience over the last day and I know through today. To Dr. Fullilove, I just want to say, "Wow! That was a very powerful presentation. I'm a little staggered right now because it was so heartfelt, and that's what I appreciate so much in public health, when we actually feel and experience the work that we do, and we are able to share that in community settings.

As Dr. Clanton said, I'm the branch chief for the Community Health and Program Services branch at CDC, and this is the branch that manages the racial and ethnic approaches to

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community health, or Reach 2010 Program, which is the focus of my talk this morning.

Reach 2010 is an important cornerstone of CDC's efforts to work directly with communities to eliminate racial and ethnic disparities, so, I want to start by giving you a little background about Reach 2010. It was launched in 1999 as part of President Clinton's Initiative to eliminate health disparities in racial and ethnic communities. We support community coalitions through Reach 2010. They are the core of the program, and we support them in the design, implementation and evaluation of community-driven strategies to eliminate disparities in the following health priority areas: cardiovascular disease, immunization, screening for and management of breast and cervical cancer, diabetes, HIV/AIDS and infant mortality. The program is principally concerned with the following racial and ethnic groups that we've heard described throughout our time here: African Americans, American Indians, Alaskan Natives, Asian Americans, Hispanic Americans and Pacific Islanders.

Now, every Reach 2010 coalition is comprised of a community based organization and they work in partnership with at least three other organizations, either a local or state health department, a university or research organization. The coalitions use local data and baseline measures to create

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community action plans to address one or more of the health priority areas in one or more of the racial and ethnic groups that I mentioned. This year we're funding a total of 40 communities across the country. We have an appropriation of about \$37 million for this program, and the average award is about \$800,000.

We have had several successes with the Reach Program. I'll just mention three. In South Carolina, the Reach 2010 trials in the Georgetown Coalition work to improve diabetes care and control for more than 12,000 African Americans with diabetes. Some of their strategies include walk and talk groups, providing diabetes medicines and supplies and creating learning environments where health professionals and people with diabetes learn together. For any of you who have been involved with diabetes prevention and control, it's a very costly condition to manage, and it's a very complex condition, or the management is complex on a day-to-day basis. Just two years after the program began, African Americans in Charleston and Georgetown, South Carolina are more physically active, they're being offered healthier foods at group activities, and they're getting better diabetes care and control. In addition, what's been particularly noteworthy about this program is that African Americans are now receiving the recommended annual tests, and those are the tests to determine your hemoglobin A1C

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levels or blood sugar levels, lipid profiles, kidney function, as well as getting dilated eye exams annually. They're also having their blood pressures monitored regularly. What we've been able to document is that the 21 percent disparity in, for example, hemoglobin A1C testing between African Americans and whites has been virtually eliminated in these two communities.

Another success story is the Vietnamese community health promotion project which organized the Vietnamese Reach for Health Initiative Coalition to prevent cervical cancer among Vietnamese American women in Santa Clara County in California. After identifying variants to care, the Coalition developed and matched a community action plan to promote pap screening by creating change among community leaders and the healthcare system, Vietnamese American medical providers and Vietnamese American families. One of the things that was discovered in this project was that in order to increase the participation of women in getting pap smears, they had to first of all work with the men in their lives, because they had actually much more influence over that decision than the women alone. The percentage of Vietnamese American women receiving pap tests has increased since this project began by 15 percent. They use community health workers in this project, and they call them patient navigators. These patient navigators have received calls from more than 1200 Vietnamese American women

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seeking information and assistance, and as a result of these inquiries over 700 women have registered to receive a pap test. In addition, 50 Vietnamese American physicians have been educated about cervical cancer, screening, diagnosis and treatment, and 29 physicians have registered over 4000 women in a reminder system. A cancer information website was established for this program and they've received more than 1200 visitors, and over 10,000 hits per month. Moreover, the breast and cervical cancer control program has been reestablished in Santa Clara County in two additional clinics and engaging three additional healthcare providers.

The last example I'll share is that the Breast and Cervical Cancer Coalition at the University of Alabama at Birmingham has engaged a variety of community-based religious grassroots and healthcare organizations in efforts to improve the use of breast and cervical cancer screening services and outcomes for African American women in selected counties throughout the state. A core working group of community health advisors, nurses, other healthcare professionals and clergy disseminate tailored information to support, to encourage and to help women access women's services for early detection of breast and cervical cancer. In Macon County, Alabama, for example, the disparity in the use of mammography screening was reduced from 15 percent in 1998 to two percent in 2003. In

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Dallas County, there was a reduction of over 70 percent during the same period. Also, 42 percent of women who reported at the start of the program that they had not had a pap test have now had at least one pap test. So we're very excited about the progress that these programs are making. They are in year three of what we call the implementation phase, and two additional years that they have to work, and we will have a new competition for this program in Fiscal Year 07.

Now, before I describe the ways that we disseminate these findings and our other research successfully, I ask two questions. What is the purpose of disseminating this research, and to whom are we disseminating this research? In many ways, the answers to both of these questions are defined in the way in which we disseminate our findings. For example, one reason to disseminate our research, as Dr. Fullilove and [Inaudible] described health impact of our work to the scientific and public health community. We make presentations at national meetings and we publish our work in scientific journals. Just last summer there was a special issue of Ethnicity and Disease that was published in July that featured the Reach 2010 Program. There were, I guess, about 19 articles in this journal, and they focused on major findings at that point that came from the Reach 2010 Risk Factor survey in 21 communities, which is the surveillance that we do from CDC, community

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surveys, descriptions of action plans and projects in local settings, information on focus groups and documentation of changes in the community after implementation of a Reach program. I'm also very excited that we are right now in the process of working with SOPHE to produce a special issue of Health Promotion Practice that will feature the Reach 2010 Program, and we've also been invited by the e-journal for [Inaudible] Disease to be featured in a theme issue on health disparities that they will be publishing next year, as well. So, in the obvious [Inaudible] that's one of the mechanisms that we use a lot.

While this is an essential part of our work, we also need to disseminate our research to a broader audience, one that will advocate for more efforts in the area of community health and health disparities. At the community level, Reach grantees have relationships with their local paper to disseminate their success to a local audience. At the national level we work very closely with our partners to disseminate our success stories to a broader audience and as a result, our programs are gaining more visibility and recognition for their continued commitment and exemplary work in the elimination of health disparities, so in addition to just the awareness of the program, we've also had several programs to receive other kinds of awards. For example, the Vietnamese Reach for Health

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Initiative Coalition that I described was one of only six organizations to receive the award for closing the health gap through programs to resolve racial and ethnic health disparities, which was an award that was presented by then-Secretary of HHS, Tommy Thompson last summer as part of a celebration for the 40th anniversary of the enactment of the Civil Rights Act of 1964.

MARK CLANTON, M.D.: One minute, please.

LEANDRIS LIBURD, M.P.H.: Let me move quickly then.

I'll skip over some of our examples. I did want to mention that we're also, in terms of dissemination, we're doing a project we call Assessing Community Transformation, and this is a qualitative research effort where we're asking five questions. I want to mention those and I'll end with that. We're asking what exactly have the projects been doing at the heart of their work, and are there similarities between projects that have been successful that distinguish them from projects that have had difficulties? What makes a project effective or ineffective in stimulating community participation? Are community members really participating at an essential integrated level, integral as community researchers, or are they just assisting at the margin? What has the evaluator's experience been like, and what strategies have they created, and where have they had difficulties? So this is a process of

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an evaluation that we think will advance the whole community-based participatory research process and be imported in the dissemination of our work. Thank you [Applause].

MARK CLANTON, M.D.: I think it's clear, when you're having fun, ten minutes is never enough [Laughter]. Next we're going to hear about opportunities in program evaluation. Dr. Derek Griffith is an assistant research scientist in the Department of Health Behavior and Health Education, a faculty associate and the Center for Research on Ethnicity, Culture and Health, and the associate director of evaluation for Prevention Research Center of Michigan PRC. His research explores four broad areas, social determinants of health, community-based participatory research, men's health and healthcare disparities. Currently he is working on an orientational capacity-building project, evaluation of the Youth Violence Prevention Center (PRC) and a qualitative study of social determinants of health. As a coinvestigator, Dr. Griffith is examining the impact of male gender socialization and institutional racism on health promotion among African Americans and Latino men. Previously, at the University of North Carolina, Chapel Hill he completed the W.K. Kellogg Foundation Community Health Scholars Program, a two-year post-doctoral fellow.

DEREK M. GRIFFITH, Ph.D.: Well, thank you for that

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very lengthy introduction. I want to begin by at least trying to incorporate some of what Dr. Fullilove said in her remarks, which of course, is challenging as we think about how to incorporate a lot of these structural factors in duly and understanding and doing more effective evaluation. One of the things that seemed to be clear from her remarks was that the dissemination and education is not just going to be for our community partners and really trying to get them to understand what we've found but it's gonna require that we educate ourselves as the researchers and practitioners, and that we really have a better understanding of how these larger social and structural factors affect the work that we do both in terms of research and in terms of evaluation.

What that then translates to is we need better theories or theories that actually incorporate these larger social and structural factors in both understanding behavior, understanding how we can intervene on behavior, so the theories that are going to underscore the interventions that we do and the theory that's gonna underscore the evaluation. I know those are three separate things and the challenge then becomes, how do you actually incorporate the theory that defines the problem, the intervention and the evaluation? And how do you do that in the context of a social and structural context? That's not something I particularly have an answer to, but it's

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something that we need to work towards figuring out.

In the '95 special issue of Health Education and Behavior, where SOPHE Articulated a research agenda, Nick Fortenborg and colleagues asked a particular question I think is relevant for us, which is, how can health education conceptualize the problem so that they can work for specific and measurable change without divorcing the problem from the broader context in which it occurs? I think that's essentially the question that we're still struggling with, how do we actually incorporate both theoretically and practically these larger contextual factors and these larger social factors in actually designing and measuring the different intervention programs that we're trying to do to change health and health outcomes, and specifically, what implications this has for health disparities. The challenge there is, one of the things we've talked about over the last day or so is, what are the differences in both defining the problem in terms of health disparities and what implications that has for the solution and determining what are the factors that you actually include in terms of addressing the problem within a particular group? If we're looking at racial and ethnic health disparities, then obviously the oppression the different groups experience needs to be incorporated into the conceptualization of the problem and the conceptualization of how you'd actually measure and

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understand in a very real context how those health and social contexts are connected within their particular lives, and therefore that would inform what you'd actually do to address it. Jeffrey Rhodes and other epidemiologists and other folks have talked about the primary determinants of health being economic and social, and somehow those factors need to be incorporated into our larger understanding of both measurement and evaluation, and in program development. One of the ways that we've tried to do that thus far has been defined as kind of contextual evaluation or participatory evaluation that has various names, responsive evaluation and so forth. By incorporating more participation from people who've actually experienced it will give us a broader view of how these larger social and contextual factors actually affect people's lives, which can give us a better understanding of what to actually include as measurement tools and as evaluation tools. That's one strong avenue to being able to advance evaluation, being able to advance our ability to understand these aspects of health promotion interventions and evaluation.

Being able to incorporate these larger contextual factors is not something that's going to be done easily, because obviously, the whole point of evaluation is being able to identify and bring down to scale something that is very complex so that you can actually determine what's effective and

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what behaviors you're actually trying to change or what factors you need to actually incorporate, and conceptualize it in such a way that it's actually measurable. To be able to operationalize a social structure that affects a particular group and that has produced disparities is obviously a considerably complex task, but it's one that social ecology has given us a direction for being able to identify at least some of the levels. How that translates to determining where the critical pieces within an ecological framework that would inform an evaluation of a program or at least inform how you'd actually measure a particular intervention is still yet to be determined. So how these larger factors kind of fit together is, I think, a part of our charge for the future. Thank you [Applause].

MARK CLANTON, M.D.: You're gonna get extra points as well. You've actually shared some of your time back, so, well done. Our last presentation, before we get to Q&A, questions and answers, is on disseminating research to policy makers, and dissemination of any variety to any target or target group is pretty important now, but I'm particularly interested in hearing how we might do that to for/around policy makers. Our presenter is Aranthan Jones. He was named senior health policy advisor for Health Congressman William Jefferson, Democrat, Louisiana, and staff for House Ways and Means Subcommittee in

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July of 2005. Prior to that he served as a health policy director for the Congressional Black Caucus Health Braintrust and directed policy positions on access to care and health disparities elimination. In addition, he served as lead health advisor to the Select Committee on Homeland Security's Subcommittee for Preparedness and Response, and during his career, Mr. Jones served as a college coordinator for the University of Illinois School of Public Health, a short-term consultant with the World Health Organization, a clinical research associate at Johns Hopkins School of Public Health, and as a program specialist with the NIH Fogarty [misspelled?] International Center. Help me welcome Mr. Jones [Applause].

ARANTHAN S. JONES, II, M.P.H.: Thank you so much and greetings for allowing me to be here this morning. I can't tell you how excited, how thrilled and how engaged I am about being here, and I want to thank you all for allowing me the opportunity. I want first of all to apologize for my short and slight delay in coming here today. It is a simple fact that you can't always plan on planes to get you back in the morning on time. But at any respect, I want to thank you all for having me here. Before I get started, though, I would like to offer a deep sense of gratitude and thanks, particularly to SOPHE, but more importantly, to so many of my personal mentors in this room today. From [Inaudible] to Dr. Aaron [Inaudible]

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to Dr. Webster, to Dr. Steven Thomas, to so many of you for making this possible for me to be here today, and also to Jamilla as well. Can I give you all a round of Applause, please [Applause]?

The reason why I'm encouraged here today is simply because I think we're still isolated between two worlds that have been defined to us by two unique individuals, W. E. DeBoyce, and Margaret B. Heckler. W.E. DeBoyce started out in 1906 in a book called *The Souls of Black Folk*, first page, first line, first chapter, "Between me and the other world, there's always an unasked question: How does it feel to be a problem?" And it goes on to say that being a problem is a very strange experience, especially one which none of us like, not being a problem. Treating people as a problem people versus people with some problems. And thus, almost six decades later, Margaret B. Heckler discovered these "stubborn disparities" and said, "If we don't do something about this situation soon, we're going to have a permanent health and healthcare underclass."

And thus, here we are today, isolated between two worlds about how we are going to figure out public policy here to ameliorate these types of problems.

And so with that, I hope to bring my presentation and purpose of how we go about submitting public policy on Capitol

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Hill, but more importantly, how health disparities and the political realities which we do health disparities in and how one communicates both the best of research, the best of design, the best of health communication to address health disparity.

It is my intent, and hopefully, during Q&A we can go through this to some degree, I want to kind of put forth four pillars in your mind as you're thinking about how you transmit research onto Capitol Hill, in particular to congressional staff and also members.

The first pillar is a simple fact of how research is delineated, and this is very, very important. Now, what do I mean by this? In the early part of this year, February of 2005 the Congressional Black Caucus met with President Bush and talked about the need to address healthcare disparities. We laid out the statistics, laid out the data, laid out all the information. We were providing him, if you will, the opportunity and also the possibility to be able to address healthcare disparities. On March 12 of 2005, President Bush announced that he wanted to change the Social Security system because black people were dying too early. And so, there was something that I think was missing between the research [Laughter] and the transition and how we go about putting across the intent, and that is to think of upheaving, if you will, an entire safety net system because we obviously can't

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address or can't change the reality that black people, Latino people, Asian people, minority folks across the world and across this country are dying prematurely. Obviously, we must have to do something to change the system versus trying to change the structure which is permitting these people to die so early. [Inaudible] is critical.

The second piece is what I like to call political hegemony. This is essentially what happens when you're dealing with political [Inaudible] that are looking for a footing from one political party to the next, because in all best of worlds, I don't think that the best of ideas all come from Democrats or all come from Republicans, because at some point, there has to be some [Inaudible] between the two. However, I never thought of our issue as being bifurcated as one side or another. The reality is that there are issues for American mainstream to deal with. But then, how do you disseminate information in a way that provides a sense of gravitas so that it doesn't get caught up in the political angles that oftentimes are used as a footing for one party versus another? What do I mean by this? What was amazing to me was in the discussion particularly around end-of-life care—and more immediately I guess we all remember the Terry Schiavo situation—was that there really was no conversation about long-term care aspects or health disparities in long-term care for minorities, which is the most

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egregious, if you will, one can imagine. And when that discussion was brought up, I remember talking with the clergy and the clergy said we should pitch it as a culture of life because, therefore, the Republicans would pick up on it and it would be a ready issue for the Republicans. But I said, if we do that, we're going to alienate the Democrats who would want to participate, and then I said that those who work within CBOs, or community-based organizations or for not-for-profits said, we should characterize this as a way of protecting and pushing social justice. And I said that immediately, once you do that you're going to turn off Republicans because they don't want to hear about social justice. They believe that in some way our society is just, we just need a little tinkering here and there. And so, how do you do that, if you will, and I hope that [Inaudible] don't get caught in those kinds of traps, in those kinds of camps.

Third pillar is policy intent. And I'm so happy that right now we just finished celebrating for some of us, the 40th anniversary of the passing of Medicaid and Medicare, and I'm glad that Dr. Fullilove mentioned the fact that this was a policy that [Inaudible] healthcare costs across the nation. What often, though, is missing is that that wasn't necessarily the easiest thing to do, and to this day, there are still gaps and holes, if you will, with how you go about doing that. What

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do I mean by this? Currently in Medicare Part B, which is the part that pays for all the private practitioners, if you will, all the payments that flow through. That is not covered under the Civil Rights Act. I repeat, that is not covered under the Civil Rights Act. The reason why is because of a gentlemen's agreement that was hashed out in 1965 that essentially said that in order for us to keep the medical societies on board, the AMA, the American Nursing Association, the American Hospital Association, we had to remove the caveat that they had to be subscribed under Part B as far as the Civil Rights Act was concerned. The policy intent, though was to assure that people wouldn't be discriminated against in health institutions, but the public policy reality is that we still have gaps and holes, if you will that permit that happening to this day. What's amazing is, when we try to move those policies, oftentimes you get faced with, "Well, that's going to create more paperwork for the practitioner, so therefore it's a bad idea."

The fourth is what I like to call interrelatable conscious upheaval of the status quo. What I mean by that is, when you're trying to communicate research to Congress, often you're asking for some change in the status quo, but one has to identify to what degree there is a consciousness on Capitol Hill to change the status quo, and how interrelated is that

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upheaval, if you will, one side to the next? So now I'm talking about situational practices. How do we go about doing this? Well the first way we go about doing this is, when you're doing your research, in particular, when many of you are doing research that is community-based oriented or participatory oriented, one has to look at how you codify your recommendations into public policy. Are they codifiable is the first thing. Now, I'm right now looking at how we can modify HEA, the Higher Education Amendment, if you will, to be able to provide some incentive for universities to do this, because I understand that many of you do not get PNT, do not get anything [Inaudible] for pushing your research into a public policy realm. But the reality is, that's where we need it to be at, so hopefully, we can begin to think about designs, fashions, scopes and caveats, and when we do that, I believe we can provide some opportunities to make that happen.

The second way of [Inaudible] is to be able to look at your advisory committees and your contact groups, if you will, or your advisory bodies. Do they have—not just the congressional staff, but also the staff of the governor's office, the staff of the state legislature, or the staff of local city councils-involvement. You don't want a situation where, the first time that congressional bodies or public policy bodies hear your work is when you're asking to solve the

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problem at that particular moment. You want them to identify with the problem as it is growing versus just delivering what can be a groundbreaking report, but often times is a hard [Inaudible] to absorb. To this day, we are still educating on Capitol Hill about the [Inaudible] and the fact that it's real. And I mean this is all sincerity. One has to understand, for those of you all here who are storming the walls of Capitol Hill, I stand before you today, humbly and disappointed, the only senior African American male health staffer on Capitol Hill for Democrats, on both sides of the aisle—only one, and that's in a pool of 21,000 staffers. I think that to me, speaks volumes of how far we are behind, so if one wants to talk about how you go about educating staff, please, I hope you're not hoping that there's going to be some turnover of black staff and minority staff on the Hill that's gonna make this process happen, because it's a slow process in the Year 2005, and we can't wait that long. So, to be able to engage, not just minority staff, but particularly staffers throughout the entire political spectrum in your work on a daily basis is part and parcel to that.

The third piece, and what I'd really like to kind of push and promote is what I like to call how you make the intersection between electability and public policy change for healthcare disparities. Oftentimes on Capitol Hill, Congress

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thinks about healthcare in three ways, well, I should say four: Medicaid/Medicare, prescription drugs, patients' bill of rights, and public health—I'm so sorry—bioterrorism [Laughter], and so in that context, it becomes very difficult to go about ameliorating minority healthcare disparities because you're having to educate people about public health, one, how the system actually works, two, and then three, how the system does not work, not function in minority communities. If you don't have a Congress that's even engaged in a way to be able to address the public health infrastructure, then how do you get them to address or be able to find a sense of motivation to address healthcare disparity? So, in doing your research, I ask that you marry, not only the public health infrastructure and it's failings, culpabilities and those kinds of things, but also related to the fact that doing minority health policy and addressing health disparities is not just good for minorities, it's good policy! It's good policy! And so, therefore, we have to build it as such.

The last two pieces—and I'll be quick and then I'll take my seat—is that if you want to communicate, and I really offer this for those of you who are doing research, collapse your research studies into a policy brief and then ask your member of congress to circulate it to his colleagues. Now how do you do that? All you simply do is pick up the phone, get a

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relationship with the congressional health staffer in that member's office and say, "I have a policy that I just released. I'm going to be publishing it in the next Journal of [Inaudible], however, I wanted to know if Congressman So-and-So would be willing to circulate this to his colleagues as part of a dear colleagues transmission to the Capitol? Keeping that issue on the back burner. Now, you ought to do that on an everyday basis. All of a sudden disparities would be this new phenomenon that would arrive. It would be something that people constantly see on a regular basis.

The last piece, and I'll close, is that for many of you, having a relationship, particularly with Congress, is critical but asking for things from Congress is also critical. What do I mean by this? There is no reason that you can't pick up the phone to ask, or to be able to e-mail a member of Congress, or his staffer, and ask them to do briefings around your work on Capitol Hill. And more importantly, when we have hearings on healthcare issues, and your member of Congress that represents you sits on that committee, you can ask them to be one of the people selected as a hearing representative to bring your perspective across. I oftentimes find it amazing that we will have a hearing entitled "Low-income Healthcare Coverage," and there's nobody [Inaudible]. And there's nobody bringing the groundbreaking work that you all are doing to the table. I

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think we can change that. So hopefully, in the Q&A session today, I'll be able to talk about how we can do that more [Inaudible But that being said, thank you so much. I appreciate it [Applause].

MARK CLANTON, M.D.: Well before beginning our questions and answers and further comments, it looks like for those of you who are interested in disseminating the evidence-base and disseminating the research, and affecting some sort of changes in social policy, public policy, or even public health, our experts have made it clear that there's a contextualization of disseminating things to various constituencies and various groups. We heard about a sort of social context that must be understood, and worked through in terms of disseminating evidence, and social contexts include both language and history as well. You also heard that there actually is a geographic context, with the concept of place and displacement. It's also important to recognize and pay attention to as we disseminate the evidence base. And certainly you just heard that the political domain needs to be approached, and you can engage that. You need to engage it frequently and you need to engage it in a more normalized way, which is by preparing the ground and providing information, maybe in a continuous way, [Inaudible] pieces to various legislators, and making the whole conversation about health and health policy is a little bit

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more normalized in terms of the Hill.

So health and medical care live in a context. We heard a little bit about some of those domains, and if you care about disseminating effectively, you have to pay close attention to those various domains. So, at this point, the floor is open for questions. You can ask questions that you've been holding onto now for 45 or 50 minutes, or you can ask questions that you've just heard, or if you just want to hear a little bit more from any of the panelists, you're welcome to ask them to share a little bit more at this point. So, the floor is open.

FRAN BUTTERFLOSS: Thanks. Thanks to the panel. First a comment for Leandris. Oh, Fran Butterfloss, I'm sorry. I'm with the Center for Pediatric Research in Norfolk, Virginia. I'm just really excited to hear that these Reach results are coming, not only surfacing now and being real and tangible, but that they're going to be published, and I think this is the kind of criticism we get all the time from the communities, saying that community-based approaches, that partnership and coalition-based approaches don't have any tangible outcomes to show. So even though they're intermediate, these screening kind of results are just so incredibly important, so, thank you and your colleagues for that.

And then, the second is, I don't even know if I can put this as a question to you, Dr. Fullilove, but what my

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colleagues and I are struggling with in Southeast Virginia is working in communities where the sense of place has already been destroyed, so when you have a community that is artificially created, public housing communities and specifically, the city of Newport News, Virginia is where this is, and when you compare it to other public housing communities where they've worked very hard in some of our cities to really create a sense of community within the housing community, and within the regular housing that surrounds it, but in this particular city, that whole structure is so bad, and there is no gathering place in the community. There are main highways and overpasses and exit ramps that divide this particular community in half and fourths, and the way the community fathers have decided to focus on this is, they're just moving the whole town out. So they're creating a new center of town, and they want to now take all this area that really is very depressed in terms of housing and literally housing that's falling apart, and since it's on valuable land on the waterfront, just completely tear it all down and make it a nice private housing community. So I guess my question is, what do you do in research work in trying to involve and engage people in research around health issues when there is such depression and lack of connectedness within that community? It's very pervasive, and community members are telling us this. It may

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be a question you can't answer. It's struggle.

MINDY THOMPSON FULLILOVE, M.D.: Well, when people live in a place together, they have rules; it has order, and even when it seems to be very bad, it's not without. And the rules are dear to people. Part of what has to happen, what's interesting, is, you have to flip the experience. One of the most powerful ways of flipping the experience is walking around places. We have found that bringing a bunch of outsiders and a bunch of insiders and just getting some maps and walking around and looking at everything, taking Polaroids—taking Polaroids is really important—and then sitting down and talking about what you saw, amazing things happen. Because as insiders start decoding everything you're seeing to you, the outsiders, all of a sudden, they realize, wow, what a lot of stuff there is, and that it has meaning to them. So, although there are levels of existence that seem disordered that aren't disordered, and that are painful and that are really the burden of disinvestment, there are other levels that are trying to organize that experience and make meaning of it. People can't help but make meaning of their experience, and they can't help but form communities. So, those things exist and are constantly being reworked in that context. So, you have to help people tap into that, and the tour is one of the best ways. We've used teach-ins in that kind of situations. What's going on here? And as

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people start telling to you, it changes how they think and it changes how they act. And as soon as they get in touch with what they love, then they're in a better position. But of course, the city fathers want to take the land, because, why put poor people on good land? It's kind of an American theory, which dates back to the Native Americans. But what is good land changes constantly. It's an interesting piece of this. So, the lesson of the Native Americans I think was, why don't you guys move on the other side of the Appalachians? Why don't you guys move on the other side of the Mississippi? Why don't you guys move on some reservations? Oh, you know what? Those reservations are on good farming land. Why don't you move to the sand? Why don't you move to that place with the black goop. And then when they moved into the place with the oil reserves and they found the oil reserves and all of a sudden the Indian had an asset, they stole the money. \$84 billion in gas and oil reserve money nobody can find. So poor people are kind of a land bank. They're the good land of tomorrow. That's where you put the poor people. Look around, you'll see this. So wherever the poor people are, that's where they're going to build in ten or 15 years. It's kind of storage. You know, like self-storage? But what happens then to the people's health is that as they get moved repeatedly, their health gets worse and worse and worse. And their ability to be creative

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and solve problems gets worse and worse and worse. They're robbed repeatedly. Whatever the people have now, it's not nothing, but it will be less after they get moved. And the idea that you can't fix these housing projects on site is just a complete lie. The idea that poor people can't live in tall buildings, the idea that you can't fix them, we've tried everything. They've never tried everything. They've never tried anything seriously. So, you're working against a fabric of lies that are justifying this very cruel policy, and that are distorting the people's experience and squashing it, so that's what you have.

MARK CLANTON, M.D.: [Inaudible] comments as well.

Please?

SANDRA QUINN: I'm Sandra Quinn from the University of Pittsburgh, and I have a question for you, Mr. Jones. When you mentioned the Terry Schiavo case, that's just one example how Congress and legislators at the state level often respond to an individual case, an anecdote of some type. They seem to sort of feed on those as a way to understand a problem. When we talk about disparities, racial and ethnic health disparities, other disparities for gender and sexual orientation, all of those, we come with the data. We don't come with anecdotes; we don't come and put a face on that disparity, so part of what I would like you to help us think about is, what's a more

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effective way to convey the message? Do we need to put faces on it? And what's the dilemma in putting a face on it if we choose that method, when in fact there are structural causes in many of these disparities?

MARK CLANTON, M.D.: That's a complex question to try to answer in [Inaudible] [Laughter].

ARANTHAN S. JONES, II, M.P.H.: I actually appreciate the question. I think it's right on. I think that the problem that we have in the body politic today is that oftentimes the problems that get solved or issues that get resolved usually are either fashionable or sexy. Terry Schiavo was both. It was in vogue, and you have to understand the political reality of the Terry Schiavo case. The Republicans [Inaudible] that because they wanted to be able to force Democrats to vote against the fact of whether or not we should keep a person alive. I mean, so that was a political angle that was there that was in place. When it comes to dealing with disparities, I actually think that there is a face on it, but I just think that people don't want to look at that face. That's a hard face to look at, because the reality is that we chose the term disparities as a social justice type term of the inadequacy, if you will, that exists in America. That's a very hard thing to deal with. That's very painful, because one has to look at the powers that they had beforehand as far as adjustment of these

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issues and these concerns. So, I think that the first thing that we have to ask, those of us in the health profession community have to find some comfort with is actually putting up a picture of American and saying, isn't this an outrage? I think we've lost that in the data, and in the analysis, that we lose the outrage of it. People were essentially outraged by the fact that Terry Schiavo was going to have her tube pulled. So we have to be able to say, well, isn't it an outrage that people die in a very brutish and mean fashion every day from these type of structural problems that we are creating and we are perpetuating? Isn't it an outrage? Don't you think so, Senator Frist? Don't you think so, Senator Collins? And so we have to be able to present it in a way that we can evoke a reaction out of them, rather than doing a passive transmission, if you will, of the information.

I think the other piece, too, we have to be able to give voice to the screams and the hollers and the gutter cries, if you will, of what it means to some suffer these disparities. And often times, that's been muted in the dance of trying to have sound and clean science. After all, we are still caught in this perplexed position of making sure the science that we're doing [Inaudible] is actually "true science." Right? and so often time there's the removal, or we eliminate the ephemeral, if you will, of feeling for the substitute of

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substance and gravitas of science. But I think that [Inaudible] is, that in communicating the role of healthcare disparities, when you're talking to a member of congress often you have to put it in a way of political outcomes. Congressman So-and-So, if you don't do something about healthcare disparities in your district for the next four years, you're going to lose four percent of your voting base. You know, and so then all of a sudden there is a need to address, because self-preservation is always the number one thing on Capitol Hill. So one has to look at those dynamics, and I could go in to a plethora of those about how to other issues as well.

MARK CLANTON, M.D.: Our next two questioners actually have notes and references with them, so we'll [Laughter]—just making a joke. Go ahead.

JEANNIE ING: I'm Jeannie Ing from the University of North Carolina School of Public Health. This is just a comment to Mindy about the global relevance of this Root Shock. I just returned from Beirut where the American University at Beirut School of Public Health is working with three refugee communities, Armenian communities, with three generations. The other are from the civil war, southern Lebanese who were moved to Beirut, and the other are these undocumented Syrian workers. It's the intervention of where a government doesn't want to recognize, and how do you sustain an intervention like that?

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KAYA LEWIS: Hi, Kaya Lewis from the Kaiser Family Foundation. Since we're talking about research dissemination, one thing we haven't touched on yet is working through the press to get information out, which can be difficult, and I'm wondering specifically for Mr. Jones and Dr. Fullilove if either one of you have had challenges or particular successes in talking about what you're doing with Root Shock and displacement, or on racial and ethnic disparities? If you could just comment briefly on how we can employ the press in trying to get this information out to the people we're trying to reach.

MARK CLANTON, M.D.: Another simple and easy question.

MINDY THOMPSON FULLILOVE, M.D.: The New York Times was publishing articles about efforts to build an arena for the Nets in Brooklyn, which is being put forward by Forest Retner. Always has to be included in the disclaimer that they are building the building, for which they used eminent domain, and that Forest Retner is their developer. So these links are deep, and the system of politicians and developers and news being involved in these efforts is, people are in bed with each other, as the old-timers used to say. So, the paper in Roanoke, which is one of the cities that I wrote about in my book, actually apologized for the stance they took on being an apologist for [Inaudible] and having helped to trash the black

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community. Consequently, having traversed that stance, when I visited after the publication of my book, it got fabulous coverage. I think that newspapers are deeply implicated and then they ease the processes of change, and coming from the powerful men and women, really the central business and political figures are engaged in doing the massive changes of cities, and the people who publish newspapers are part of that, so telling the opposite story is difficult.

MARK CLANTON, M.D.: We have time for one more response.

ARANTHAN S. JONES, II, M.P.H.: I think as far as getting the media, when it comes to Capitol Hill, it's a difficulty, because Capitol Hill in itself is an experience for most of America, and I often tell people, when I tell people when I ask them what's the business that Capitol Hill is invested in, many people often believe that the only thing that we can do is cut taxes, which I guess in a way is somewhat true, but the reality is, we're in the business of deciding life and death, and if we could ever get that message out, it would be easier to get out the message about racial and ethnic health disparities. But, the problem, again, is that usually media itself, particularly the big conglomeration media, is about happy feelings, so how do you transmit, if you will, problematic aspects of our society without putting on a face of

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happy feelings? I mean, after all, this is the same media that won't even show soldiers who fought in Iraq who had died and were coming back home. I mean, that was a gentlemen's agreement, you know. [Inaudible] official policy that blocks media from doing that. There's official policy that blocks actual families from going and seeing their people, but not an official policy that blocks media. And so I think that there is an issue of you convey the painfulness of it. Now oftentimes we get fixed up on an individual, but then that will also be counterproductive to our efforts, because if you present an individual suffering healthcare disparities, you get the response, "Isn't that sad? Isn't that unfortunate? Oh, poor man, how can we help you?" And what we're trying to get at is the structural components. What does it mean for the site that creates the structure, for instance on reimbursement rates as far as healthcare's concerned, that leads certain people and also [Inaudible] that leads to certain people who have a high level of comorbidities to not get services. How do we deal with that in a very functional capacity? And then I think the creating story lines about that are easy to do, but difficult for the American public to absorb, and when it comes to Capitol Hill, it's even harder, because then you have this reality that most people believe that all people on Capitol Hill are corrupt anyway, and so there must be some political

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angle to this whole aspect, anyway. And oftentimes, for the cheapness of party affiliation or party gain, it usually gets collapsed in that, where the party will go out, and push. I'll be honest with you, I have worked and work on behalf of the Democratic machinery if you will, within Congress when it comes to [Inaudible] policy. However, I do know that the only reason why [Inaudible] policy was elevated to the level of leadership is because Senator Frist was making sure [Inaudible], and then all of a sudden it became, we can't do without [Inaudible].

MARK CLANTON, M.D.: I'm afraid we'll have to stop there. I just realized why they asked me to moderate [Laughter]. I weigh more and I'm taller than anybody at this table [Laughter]. So we're about 20 minutes over, but please, we'll take this last question.

JAMILLA RASHEED: Okay. I wanted to take advantage of having Mindy here. Jamilla Rasheed, CDC. Mindy is a member of our workgroup on developing the CDC research agenda, and since she's here and very busy, I just want to ask, do you have any specific suggestions on research agenda needs, not just for SOPHE, but for CDC that are sitting there in your head and you can just like, throw them out right now [Laughter]? Just any pearls of wisdom, any thoughts on the process or ideas [Inaudible]. How I'd like to spend my summer vacation.
Related to the building environment issue

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MINDY THOMPSON FULLILOVE, M.D.: Boy, I think about that day and night. I think that what this process while studying urban renewal that was shocking was that the place that people had been moved to after urban renewal in various cities no longer existed, and now the people had gone someplace else, and for the most part, that didn't even exist and they had gone someplace else. And thus, there's an untold story of decades of displacement of poor populations in the United States that has not stopped. All the geographers would say if you know the last five maps from the Census, you can predict the next map, so the next map is, those people will be someplace else. I think we don't even begin to know the story, but you can read it on the landscape of every American city, and this weighs on my heart.

MARK CLANTON, M.D.: Well, what I'd like to do is invite you all to accost our panelists outside and after the session, ask the questions that you really want to ask and get the answers you really want to get. I want to thank you all, in particular, thank you to our panel for [Applause–Inaudible]

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