

Exploring Mechanisms for Public Engagement
Toby Citrin, J.D. and E. Yvonne Lewis

DR. WILLARD: Our next speakers will be a team presentation from Yvonne Lewis and Toby Citrin. Ms. Lewis is the executive director of the Faith Access to Community Economic Development Organization in Flint, Michigan. She previously worked with Mr. Citrin on the Genetics Policy in Communities of Color project at the University of Michigan, where he is director of the Michigan Center for Genomics and Public Health and director of the Office of Community-Based Public Health at the University of Michigan School of Public Health. A lot of public health here.

The two of you will have a half hour. You can divide that any way you wish. I'll turn it over to you, and thank you both for being here.

MS. LEWIS: Good afternoon, and thank you. It is our pleasure to be here. As you can see, we're a tag team. This is work that we've done over a number of years now in Flint and Genesee County, in partnership with the School of Public Health and our communities.

Our purpose this afternoon, as you can see in our outline here, is to talk about three engagement projects that we've actually utilized to talk about the issue of genetics and other chronic health issues. We want to share with you what we've learned from those projects.

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We also want to make some suggestions about how we might be able to apply what we've learned to this large population study. It is an interesting project, and we hope that what we share with you this afternoon will stimulate some even more interesting conversations.

MR. CITRIN: Thank you, and thanks from me also to the Secretary's Advisory Committee for this invitation.

As Ms. Lewis said, we want to do a very quick summary of three very closely related projects sequentially, which all achieved a level of participation and engagement from which we think we can learn a lot of relevance for this large-scale population study that we've all been discussing.

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The first of these projects is the one labeled "Communities of Color and Genetics Policy Project." It was funded by the National Human Genome Research Institute, and its goal was to engage communities of color, in this case African American and Latino communities, at the grassroots level to engage in dialogue about genetics issues, and to formulate recommendations for policies that would enhance benefits and minimize harms to these same populations.

The project followed a partnership model, partnership between three universities, in this case the University of Michigan, Michigan State University, and Tuskegee University, in turn partnering with 12 community-based organizations in Michigan and Alabama, each of which had constituencies and a population served, a population represented either in the African American or the Latino/Hispanic community. As your Chair suggested, Ms. Lewis played the leadership role in one of the key organizations at the community level, the (inaudible) organization, in Flint, Michigan. A couple of other people who are either going to be in the room or presenting to you were very much involved in that project. Vince Bono, who some of you know, played the role of

both researcher and facilitator to a couple of the dialogue groups. Dr. Pilar Ossorio, who is on your agenda later this afternoon, was one of the valued members of our national advisory committee.

We started with a series of focus groups in order to tease out issues of concern, these following a basic educational module on genetics research, the path that it was following, and where it might likely lead. Then following those focus groups, each of the community organizations hosted and sponsored a series of five dialogue sessions, typically attended by approximately 20 members of their community, most of whom made repeat participation to dialogue sessions over the course of these five weekly dialogues. So it involved a little over 200 people, and these sessions typically ran about a couple of hours each, so the investment of time for each of these 200 people was approximately 10 hours over these five weeks.

The community organizations, and Ms. Lewis will say a few more words about their critical role, were partnering with us in all aspects of the project design and implementation, including the joint selection of facilitators and, extremely important, the selection of the place, time and mode of dialogue. So in our case, the place where the dialogue took place was the place where dialogue typically takes place, in the communities who were engaged in the project, as hosted by their community organization hosts.

The community organizations worked together with the academic team in developing the process, in implementing the process, and then, extremely importantly, in crafting the summaries and the reports and the ultimate recommendations which were used to describe what came out of the process. So the voices of the community were heard throughout the project, from beginning to end, including the ultimate end of the project where the community organizations and academic partners met with policymakers in Michigan and in Alabama, sharing the recommendations, and then had a two-day visit to Washington, where we met together with our community partners, with members of Congress, Congressional staffers, and the President's genetics advisors, again sharing the policy recommendations that came out of the project.

I'm not going to go through the recommendations. It wasn't what we were asked to do today, but just to tell you they all fell into seven topical areas: the area of access; of education; playing God/perfect children; the right to genetic privacy; genetic research, which of course was very important in terms of the presentation we're making today; genetic testing; and then perhaps the most important issue of all which cut across all the others, issues of trust and distrust.

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MS. LEWIS: As a result of one of those policy decisions, one of those important components that Toby mentioned was the education. When we were engaged in the project in those dialogue groups, some of the information that came out particularly indicated the need for additional education. We've heard that already today.

So as a result of being involved in this project, we had the opportunity to become involved with the Genetics Education Needs Evaluation project, which was funded by HRSA, and there were two communities, one in New York and, of course, we in Michigan. So we built upon the relationships that we had in the original project to develop the gene project in Michigan, but we added an element to that, because whenever you talk about community engagement, it's important to identify those groups that are particularly going to be affected by the information that's being shared.

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So there were several community-based organizations that included churches, that included social organizations, Greek organizations, and adding to that was a school system. So the Lansing school system was brought into this project to look at the education needs of African Americans particularly, because that was our focus for this project.

In working on this, we continued to bring together representatives from the community to work through what those needs were. How do you determine what the educational needs are? So part of that assessment was actually having community members be provided education about genetics, basic education about genetics, and then asking them the question what do you think you need to know? What are some of those important conversations that you believe need to happen to help you be better prepared, and how might that education be facilitated? So from that collaborative process, a series of information was gained, and then we culminated that with a town hall meeting, reporting back to the community.

The interesting thing and most important element of this was that it was not a one-time event. The same people were brought back to the table several times to work through their recommendations and suggestions. So you flesh those out, come back, and then home in on what do you think is most important. Following that small group discussion, that small group still being about 20 people or so, a formal town hall meeting was organized to help the broader community understand what the elements were of that project and how to best communicate that, particularly what we call "checking in," to see if what we said in the smaller groups was really representative of what the larger groups would say.

One of the most delightful things we found at that town hall meeting, which was attended in Flint by about 100 people or so -- the delightful thing was that the quotes and the information that we said, they responded. I wasn't at that meeting, but I can relate to those comments that were made. People were saying things like we need education because we're not sure what genetics means, we're not sure about how it will impact us. We have some concerns about how the information will be used and who will be responsible for the information once it's obtained.

So the collaborative process was very, very important. That further led us to using this same kind of concept in another statewide initiative in Flint that looked at improving cancer outcomes of African Americans in Michigan. We continued to use the process that says community is responsible enough to help determine what its needs are and how those needs can best be addressed.

So from this, working with our department of community health and a number of community leaders from across five cities within the State of Michigan, because we realized that African Americans particularly are dying 33 percent more often from cancer than any other ethnic group -- but our question remained how aware of this is our community? So we needed to raise the level of awareness, we needed to raise the level of knowledge and communication about this, to reduce the myths and, of course, in this case, engage people in screening programs.

One of the things we found out in our discussions about this is how often the issue of genetics would become a part of that conversation. The concern about total health would become a part of that conversation. So when you move from a particular issue, if you're talking about genetics, this conversation process can be used to talk about larger issues as well. So we learned quite a bit from that, and we'd like to now share with you some of the specific lessons that we learned from these three engagement projects.

MR. CITRIN: Next slide, please.

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So one of the things we learned, certainly from the Communities of Color project, addresses the first question that we were asked by your staff as to whether the public would support a large-scale population study, and I think it's fair to say from the discussion on genetics research that took place in all these communities that the answer is yes, if; that there is, as Joan Scott just mentioned, an underlying faith that science has a lot of potential to alleviate human suffering, reduce disease and, in fact, reduce health disparities, and that we should allow science to progress provided that it's done in a way that is attendant to the issues that you all have been bringing up and that we're bringing up in this presentation.

We learned that if we are to achieve full engagement of the community, the community needs to be involved in all stages of the particular project or study. This means involvement as the study is designed, involvement in developing the various instruments and materials that are going to be used in the study, involvement in the way in which the results of the study are going to be reported to the public at large and to various subsets of that public.

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MS. LEWIS: Now, as Toby mentioned, we're talking about being involved as an equal partner, not just as a passive voice or an endorsing or co-signing voice. As a result of that, in much of our discussions we understand that distrust comes from a history of a concept of them studying us, with the benefits being for them and not for us. The conversation so often happened, and we just had this a few days ago when we were talking about the issue of infant mortality, that 20 to 25 years there's been a lot of research done and we're still seeing the same kinds of results in many of our communities, even worse when you ask where is all this research and how was it translated to community, how was it utilized by community. In most cases, we have to answer the question that it was not and did not benefit the individuals who were being directly affected by it.

So there's still this huge question with this issue, which is who is going to be really responsible and are we going to be intimately involved in discussing how this will work?

The other great segue from that is all the history around race and racism in this country, particularly in the United States of America where it was a Constitutional issue as it relates to African Americans, and it still is today. Those things are not erased. They're not erased in individuals' minds, they're not erased from our day to day or institutional processes, which continue to keep that as an issue that will prevent us from being successful in delivering a good product, because the trust isn't there.

Toby said if, if we can work on being open and honest and very frank about this is a discussion that needs to happen, a very deliberate discussion, that it is purposefully intended to be a part of the conversation, because trust comes from co-ownership. It comes from really believing that you are an integral part of it, not somewhere along the line but in the initial parts of the discussion. So for me personally, I'd like to thank this committee, because we went through a little bit of a discussion trying to get here today, and you made some allowances for that. But certainly as a representative of my community, I can attest to the fact that there are opportunities for us, and we'll talk a little bit further about what that really means to the community as we think about the importance of engaging a large number of individuals across this country to address this issue.

MR. CITRIN: Next slide.

We learned something about education that most professionals in the field of education already know, and that is that education is most powerfully done if it follows engagement. If students are engaged in the subject, students will hunger for education and learning. If they aren't engaged, then all you might want to do in beaming education to them is not going to have much result. The sequence of our projects actually was from an initial recognition of relevance of the project to the community, which brought engagement in the project, and having been engaged, there was a continuing desire to learn more.

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MS. LEWIS: Next slide, please.

The other thing that we learned as a part of all of this is that the community's expectations are raised when they have been engaged, and that is clearly a difference in the amount of involvement a community might give. We still have individuals -- and this is after five years now -- who meet us on the street and say what's the next thing happening in genetics? What are we going to do to follow up on those issues? So being involved in it from a community-based perspective keeps it relevant and in the forefront of individuals' minds.

So having raised that level of expectation, it's clear that they must understand what the expectations are. What is the purpose? How is it designed? Why is it designed? Who will benefit from it, and what will be done with the outcomes? What's the purpose? What's the ultimate goal of this involvement? Not fulfilling these expectations continues to lead to distrust and ultimately the opposition which could really sabotage the effectiveness of a project over time.

MR. CITRIN: Next slide.

MS. LEWIS: Additionally, community-based organizations which we represent are valuable, and we say intermediaries. It's that intermediate step. It's not going to be the case that you will be able to engage every individual of this 500,000 or million folks, but certainly there will be a need for some organized group within the community to maintain some synergy or some consistent engagement, consistent opportunities for dialogue. So as we developed our projects over time, they were designed so that community-based organizations would be seen in a leadership role and continue to be partners in the study.

The other unique thing that I think we've developed over time that is really beginning to evolve is the connection on a local, state and national basis of collective community-based organizations understanding these issues, particularly as it relates to research and prevention research. We're a part also of the Prevention Research Centers of Michigan, funded by the Centers for Disease Control. As a result of our involvement since 1999, there is now a National Community Committee that is representative of community-based individuals who are considered advisory board members of all of the centers as a part of that, and we've been meeting regularly for the last few years looking at how we can collectively gain some understanding about how to engage in community participatory research. It is so important to develop the capacity of individuals within our community to understand the research process, and we use a phrase in our community, "bench and trench." We believe very strongly that science has its place, and we call that the bench, but we also believe very strongly that there is expertise within communities that represents the trench where the work is actually going on, where the experiences are actually happening outside of a research framework within an institution, but bringing that into the community.

So when you work with community-based organizations at these levels, particularly national networks, when you're looking at a project like this, you have the opportunity to really expand the level of involvement and some collective thought about how this will continue to happen.

MR. CITRIN: And as a footnote to these comments about community-based organizations, we found that there was quite a differentiation in our experience of who comes to sessions, on-site sessions, when they're hosted by community organizations, as distinguished from people coming to sessions that are hosted by other organizations from outside the community. Here we did depart from aspects of, for instance, the Oregon Health Decisions movement, which found very much, as Joan Scott just reported, that it's the more highly educated people who have a particular stake in this or that genetic disease or, in the case of Oregon Health Decisions, in the health system itself who come to the dialogue.

When the community hosts the dialogue through their own organizations, you really avoid that kind of differentiation because people are simply coming to where they normally come to discuss and to formulate recommendations and to formulate advocacy.

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Ms. Lewis mentioned the work that we have done together over the years on community-based participatory research. It's probably clear that the large-scale population study we're talking about isn't going to be able to be conducted exactly with all of the characteristics of the sort of gold standard of community-based participatory research, but there's a lot to learn from that research that is of relevance to a large-scale population study. The way in which knowledge is bidirectional, coming from the community to the researchers, and from the researchers to the community, can make a project much stronger, much more relevant, can make the instruments more powerful and more accurate.

The ability of people from the community that's being studied to actually have a voice in the project itself and what it leads to can help bring the participation in the first instance. Here I would suggest that there is a role that this style of research can play in education, and I guess here I part company to some extent from the sequence that my esteemed colleague, Dr. Kardia, was suggesting this morning of infrastructure first, project next. If the project, in fact, does engage the community and is fully participatory, then the project can be a vehicle for community education as it moves along, as it's being planned, as it's being implemented. One does not have to have the education first if the participation is going to be there.

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So the ultimate summary, and it's why we chose the title we did for our joint presentation, of what we learned from these projects if really encapsulated in the word "partnership." If the project is going to be successful, it needs to be a true partnership between the researchers, those who are researched, and those having a stake in the research. We really don't like the word "consultation." Consultation sounds like a train is running over here and periodically you sort of check in and ask for advice. We love the word "partnership." We think that's what's going to lead to full participation and engagement.

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MS. LEWIS: We indicate here that the process for partnership building must be evaluated continuously, because at times it's not so much how it's being done. At times it's more important

what's being done. Unless people are feeling a strong sense of involvement, what you end up with still may not be the product that you want, still may not be utilized in a way that would be in the best interests.

So along with researching and evaluating the research itself, we suggest that continuous evaluation of the process and that partnership building be done as well. That will help lead to developing a common language, developing a common understanding, and ultimately developing the common goal and achieving that common goal to ensure the progress, identifying what the stumbling blocks are over time. When those identified stumbling blocks become clear, then there's also the possibility to develop strategies along the way so you don't get down to the end of the project and figure out, oh, we should have fixed that five months ago.

So we're continuing to find that evaluation in large-scale projects like this are a real challenge, because when you're working with people over time, particularly when they may be in a volunteer situation and just being asked to offer their time and they're not seeing the true benefit, they're not sitting around the tables like this, hearing the ongoing dialogue, something gets lost in the translation. So there is a continuing need to work on that because community involvement is such an integral part of the process of capacity building.

If we can build the capacity -- and I may repeat this a number of times, but if we can build and maintain the ability of individuals in the community to understand this, when you get ready for the next part of it, it's not as difficult because the language is clear. I've heard a number of acronyms this morning that I never heard before, but now that I've been exposed to them I'll go back and read a little bit and I'll figure that out. But this raises my ability, then, to go into the community and say here's what's going on, here are some potential implications of this, and here are some things we need to think about.

So having the ability to do that ensures that when research is done in the community, you have a higher level of understanding, which means the project can move more swiftly and more effectively.

MR. CITRIN: Next slide, please.

Now our final comments are an attempt to apply what we've learned through these three projects to the proposed large-scale population study or resource.

It's clear, and you've already identified this, that this large-scale study proposes a major risk of generating distrust among vulnerable communities, particularly communities of color, and the reasons you have identified and we've spoken to, so I need not repeat them. But it's also clear, it seems, that the avoidance of that distrust and the achievement of participation and support is dependent on the concept of co-ownership of the concept across the communities that are most at risk from the study or that perceive the most risk from this kind of a study. If you have a sense of co-ownership and partnership, you will remove the major cause of the distrust and potential opposition.

On the positive side, if you do achieve this kind of sense of co-ownership, you have powerful advocates for what Dr. Kardia referred to as infrastructure that's necessary, what Dr. Khoury referred to as the two-pronged approach, what Dr. Collins referred to as the need to address these issues of education and policy. This can all be done together with powerful joint advocacy if one has the engagement and the partnership to start with.

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MS. LEWIS: Another very important thing that we believe we would want to have considered in applying what we've learned is that the decisionmaking and planning needs to start now in having community engaged. Just a phrase is if you start right, you can end right. We cannot expect to have the buy-in of community if it is perceived that the train is already rolling down the tracks, there's no room for any modifications or adjustment, there's no room for voice.

If, in fact, we want to be effective at all levels, at the federal level, at the state level, at the local level -- and I recognize that sometimes individuals come in a community -- an example was given in the town hall meeting. You come into the community, you have a conversation, and that's wonderful because people do feel like I had something to say. But they're going to sit back and wait and see what happens next, and when that same thing comes around again, the question becomes is this actually the same thing? What did you do with the information we shared with you the first time? So at a local level that happens, but it needs to happen more at the state and federal level, because when policies are made, some of what happens at the local level doesn't always get filtered up. So unless those voices are there at the time some of those final decisions are being made, things may get lost that are so integrally important to the success of that when you get back to the local level.

DR. WILLARD: Just as a time check, if you can try to finish up in the next five minutes or so, we're half an hour into this.

MR. CITRIN: Okay.

MS. LEWIS: So particularly as it relates to the health disparities, it's important that the process be explicit, the study process be explicit in addressing the issues of race and racism, and that the individual representatives of the racial and ethnic groups are an integral part and meaningfully involved in developing the plans and methods.

MR. CITRIN: Next slide, please.

This is a national project. Therefore, it's necessary to do the kind of connection with community at the national level, as well as regional and local. The number of national organizations that have local chapters and that represent these same constituencies can become partners in this project. As examples, we mentioned the National Urban League, the NAACP, the National Organization of La Raza, the AME Church, the National Medical Association, its counterpart in the Latino/Hispanic community, and on and on. These are organizations that can create the kind of buy-in for the project that are all interested in health issues, that also can translate and filter down through local chapters of these organizations into the kind of grassroots dialogue and engagement that Ms. Lewis and I have been talking about.

The National Community Committee, of which Ms. Lewis spoke, can be an extremely valuable resource because here you have community organization representatives in 20-some states, all of whom have a great sense of the worthwhileness of research and the role that community can play in research.

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MS. LEWIS: And I'm sure you have this handout, so I'm going to summarize the next two slides that talk about community-based stakeholders, as well as community-based dialogues and to say

that the community's signature must be there in the materials and as part of the engagement process, and of course in the dialogue process to keep the process going, to keep it open and flowing. So there needs to be a continuous opportunity for this exchange.

MR. CITRIN: Next slide, please.

You have to emphasize, along with the word "partnership," the word "dialogue." We like that word because it has to do with an exchange of perspectives and the ability to try to understand what the other perspective is. So if you can foster through these networks dialogues that involve scientists, professionals, practitioners, public health people and grassroots community people, each can get a better understanding of the other, what the project is all about, and what people's concerns and interests are.

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MS. LEWIS: The next slide focuses on the role of media, and I think we all recognize how important media is to framing, shaping and maintaining the messages and pictures in individuals' minds. So it is important to have a real concentrated focus on how the media is utilized to ensure that lack of trust and fear do not become the predominant part of what people understand.

MR. CITRIN: Next slide, please.

Mention was made earlier today about a national institutional review board, and much has been written about the kinds of studies that pose risks to groups as well as individuals, and the need of IRBs to consider those risks, those group risks, as well as individual risks, the need for informed consent materials to reflect the culture and the sensitivity and the language of the communities, and to reflect these group risks as well as individual risks, and to ensure that IRBs who do have a review role are reflective of the communities who have these risks.

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The study design -- and this was spoken of earlier, so I'll just mention it -- does need to have at least a process to give some confidence that the results of the study, both the ownership of the data and how this data is going to be used, are for the benefit of the community and will not be used only for people, for instance, who have access to health care benefits, et cetera. Now, it may be difficult to give these kinds of assurances at the beginning -- next slide -- but the process of the project, the very fact that it is a partnership, that there is advocacy built into it, and that there is, as Dr. Collins mentioned, the recognition up front that the ownership of the project is in the public and will remain in the public, these can go a long way in allaying concerns that the results of the study are going to be used for somebody else's benefit and not ours.

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MS. LEWIS: I want to summarize the next two slides, the continuous evaluation by the participants, by saying again that we cannot wait until the end. The capacity building is so very, very important to engage trust along the way for the research itself, and the importance of a shared language. The next slide talks about the fact that even the language that's being used is critical, moving from calling individual study participants subjects to actually engaging them as partners in the process; and, of course, continuing the importance of communication so that there is an open understanding of what's going on.

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So in conclusion, we thank you for this extra few moments and we'd like to say that -- next slide, please -- we believe that the successful implementation of this contemplated large population study depends on whether the study is perceived as a project carried out by the public or conducted on the public. Is this truly going to be a project that is fully engaging? Partnership is absolutely the key to success.

DR. WILLARD: Thank you very much. That was wonderful. Thank you for sharing the experience you both had in Michigan with this.