

MCHB/ DSCSHN June, 2005 Webcast

MCHB Genetics Needs Evaluation Project

PENNY KYLER: Good afternoon. This is Penny Kyler. I would like to welcome you to the MCH come.com webcast today. Before we get started, I'd like to tell you a few things that are technical information. Slides will appear in the central window and should advance automatically. The slides will change with the speaker's presentations. You do not need to do anything to advance the slides. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the message window. We encourage you to ask the speakers questions at any time during the presentation. Simply type in your question in the white message window on the right of the interface, select Question for speaker from the drop down menu and hit Send. Please include your state or organization in your message so that we know where you are participating from. The questions will be relayed to the speakers periodically throughout the broadcast. If you don't have the opportunity to respond to your questions during the broadcast, we will email you afterwards. Again, please, we'd like to encourage you to submit questions at any time during the broadcast. You can adjust the volume of the audio using the volume control slider, which you can access by clicking on the loudspeaker icon.

Those of you who selected accessibility features, when you registered, you will see text captioning underneath the real audio player. At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation.

Please take a couple minutes to do so. Your responses will help us plan the next and

future broadcasts in the series and improve our technical support. The MCHB Genetics Needs Evaluation project was a five-year project to investigate and improve consumer access to genetics information resources and services. Launched in 2000, the project was managed by the March of Dimes under a cooperative agreement with the Maternal and Child Health Bureau of the health resource and services administration. Two other national partners were Family Voices, a national grassroots network of families speaking on behalf of children with special health needs and the genetic alliance, a coalition of professionals that promote the interests of children, adults and families living with genetic conditions.

The central mission of the project was to develop a community-based participatory strategies to improve access to culturally appropriate information. To assist under served populations and making informed choices about their health. In order to accomplish this goal, are the national partners joined with two communities in the states of Michigan and New York and received input from other stakeholders, including a variety of HRSA funded grants from the early 1990's.

Next slide. Why did HRSA fund this project? Advances in genetics have created new opportunities for improvement in health care and new challenges for learning. In order for the public to benefit from these opportunities, access to genetic services in the form of information, genetic testing, genetic counseling and other services must be readily available. Public awareness and knowledge about how genetics impacts personal health care decisions make processes or -- excuse me. Public awareness and knowledge about

how genetic impacts personal health care decision making processes are low. Individuals may not make the most informed health care decisions. Next slide. Although many consumer advocacy organizations and government agencies have developed informational materials about genetics, even the most motivated individuals, those who have no genetic conditions in their families, often have difficulty accessing and understanding the information. The information may not be culturally appropriate for all individuals. It may not even be what information consumers need and effectively use.

Next slide. Today, you will hear from four speakers, Aida Giachello, Mary Zoquier-Estevez, Othelia Pryor and Teresa Doksum discussing community-based participatory research, the communities themselves, and outcomes obtained during the grant and lessons learned. We hope in the end you will be able to envision how important community is to the genetics needs. Our first speaker is Aida Giachello.

AIDA GIACHELLO: Good afternoon. My name is Aida Giachello. It's a pleasure to be a part of this important event discussing participatory, specifically participatory action research in the context of genetic education. My presentation objectives are to briefly describe the community based participatory action research methodology that guided the work of one of the GENE Project demonstrations that we will be hearing more about. Let me begin by stating the GENE Project vision. The long-range vision of the project was to create a collaborative network for the development and dissemination of culturally appropriate human genetic information that will assist individuals in making informed choices about health. The overall goals of the GENE Project are. Number one, to develop

a model of community-based participatory consumer genetic education in partnership with populations who are underserved and under represented.

Two. To strengthen a system national and local partnerships that would help to sustain, replicate, and disseminate the model. In an effort to achieve the goals of the health resources services administration and March of Dimes have partnered with community-based organizations to engage in community genetics demonstration projects. The selected communities for this project are Washington Heights Inwood which is located in the northern part of Manhattan, in New York City and Flint and Lansing, Michigan. You will be hearing more about the work of these communities in a few minutes. My focus at this point is to describe the Community-Based Participatory Action Research which is the conceptual framework that guided the work, particularly of the Washington Heights Inwood community. So let me begin with the definition. When you think or read or describe Community-Based Participatory Action Research, you're really referring to a family of research methodologies that pursue research objectives with active community participation and with the ultimate goal to engage in some immediate action.

So the key word is community engagement and action. Community-based participatory research tends to involve all the people in the research process. So they get involved from the formulation of the research problem, and in many instances from the moment of preparing the grant application, if there is one, and to also assist in instrument development, data collection, analysis, and write-up, including then all the dissemination of the findings. You also seek solutions to community problems through partnership and

collaboration. And the emphasis is community engagement and mobilization. And this is critical because this type of research is a process of mutual empowerment for the researcher and for the communities representatives that are involved because they're actively learning in the process and being impacted in terms of the kind of work that they are doing on a daily basis.

Some of the potential stakeholders to be mobilized in the area of genetics can very well include, number one, persons who are directly affected by the problem. Particularly those with a genetic base condition or people who may have a predisposition to some genetic-based condition. It could also include parents, spouses, and significant others, health care providers, schools, and other health and human services organizations representatives, faith community, policymakers, local, national consumer organizations, and local and federal government. Key in the process of participatory action research is this process of consciousness, because while the community comes together with other stakeholders discussing areas of mutual concern, they're developing this kind of awareness that leads to a state of readiness that can be enhanced through leadership development. And in this process, residents and other stakeholders become effective agents of social change.

Also, it provides the opportunity to benefit the community with programs or services. And it is a way of institutionalizing activities in the community. The participatory action research embraces again personal and community empowerment first as a philosophy, as a process in the way in which they do business, and then the outcome of the entire activity. When we examine some of the differences between traditional or academic type of

research with community participatory action research, in your slide you have a number of potential differences that could be highlighted. The mainstream traditional research and academia tend to be rigid, they tend to have limited community participation or no participation, researchers or funders tend to be in control in setting the agenda and really determining how things will be done.

And the end results. And the project ends usually when the assessment or the research activity has been completed, or when the funding has ended. In partnership with community is not really based on an equal basis in terms of providing community financial resources, technical support, and sharing data and other benefits of the research process. The participatory action research, on the other hand, tends to be flexible. There is a great deal of community participation. There is a share of governance in terms of decision-making. The real action starts when data is analyzed and the community has this sense of ownership of the process, so they could very well guide the action they should be following. Researchers, funders share financial resources, provide job opportunity in a diversity of form. Provide technical support and training to those stakeholders or organizations that are actively involved in this process.

Now why is it important to focus on minority and underserved communities for the GENE Project? Well, very clearly in the year 2000, the census data clearly indicated minority represented at that time more than 29% of the U.S. population, very clearly an accelerated growth. Another factor could be the recent research has provided evidence of social and health disparity. That's why more than ever we're talking about this kind of topic. Then

there is limited research and data on minority and underserved population related to genetics in general, and genetics education in specific. Now, the next slide really shows, figure 1, it shows really the process that really guided the work of Washington Heights Inwood coalition genetic education activity.

Number one, in a series of boxes, you have a series of processes that involve what we call community entry and engagement, because it was the project leaders trying to establish partnership with community-based organizations. The way they did that was touching base with gate keepers, key persons, influential people in the community. And they from those early encounters were able to give a list of other potential key leaders. And so the project staff were able to then engage in face-to-face meetings, or telephone interviews, to be able to assess the level of interest and potential support in addressing genetic education concerns and to be able to mobilize them, potentially mobilize them in some fashion to be able to get the work done. And so that led to having, after those face-to-face and telephone interviews took place, there was a call for a community forum to take place in the interest of genetics and for minorities to address genetic education and from there was a process of consultation about whether or not a community wanted a project like this in their area and what kind of shape or structure that should take.

In this case, it was a coalition that was formed. The GENE coalition of Washington Heights. Then once there was a commitment to work together, the process was giving them an orientation about the project about what are the goals and objectives and the needs. And then strengthening the coalition members so they could develop

cohesiveness, develop group norms and goals and objectives and other activities that facilitated the group process. From there, begin to engage in what we call capacity building through training, getting them information by having speakers and experts talking about genetics. We call it Genetic 101, because some of the community that came together had limited or no knowledge about genetics, including some of the leadership. So really getting them to understand this whole area of genetics and some of the reasons, scientific research, so they could understand further and be further committed into addressing this problem.

Then the committee began to receive training on a series of applied research methodologies in deciding what kind of need assessment they want to be collectively involved to be able to assess the problems in the community as they relate to genetic education. And so for that reason, once the training took place and they agree on the methodology, then we engaged and facilitated the process of data collection. They specifically wanted a community survey on genetics. They specifically wanted a focus group with providers and consumers. They wanted to look at other socio-economic data that impacts their community and they wanted a sense of what other community resources may be addressing genetics, for genetics screening and testing and treatment. Once that process was completed, then the next step, step 5, would be more the community engaging in the process of disseminating findings, through community forums, town meetings, professional conferences, developing manuscripts for potential publication.

Then the coalition right now is in the stage of reorganizing themselves because in that process of dissemination, they also develop an action plan based on community input about what should be done as a result of the data that will be gathered. And then that action plan that was developed will include clear goals and objectives, strategies to be followed. It also delineates some of the strengths and limitations in engaging certain activities and also it lists resources in terms of social, capital, and human, but also financial. And then it lists the evaluation process that should be followed. The next charts gives you an overview of what exactly is the process the coalition is moving. First trying to understanding the cultural aspects in again.

The whole partnership through coalition and engaging in training and capacity building, in strengthening the group relationship, to engaging a process of action planning through development of logic model kind of framework. And then from there, engaging in need assessment and starting the phase 2 which is the implementation of the community action plan. Some of the ideas that the coalition leaders have been discussing and which are also listed in the action plan is continually building community capacity through training. Because there is a further need based on the community survey of areas of people in the community want more knowledge and information and training will be aimed to consumers and health care providers. Then it will define needs in terms of the policy perspective the community system and how can we impact health and human services organizations.

Particularly as they relate to making sure that there's ways of community accessing genetic services and that those services are not only cost appropriate, but culturally

competent. And then there is a whole series of potential plans under consideration about community awareness campaign and education around genetics. And then how we could be able to impact a specific individual and family to do genetic family history and changing among those that are predisposed to developing certain conditions, how can we impact lifestyles so they can change certain behaviors to delay or make sure that those conditions would not be developed. So in summary, there's a series of benefits of community participatory action research.

Number one, it has the potential, and in terms of our experiences, it provided the community with the opportunity to understand and to address genetic issues. And this was one of the things that we early on were concerned about because we saw the genetics would not in the top agenda of any community leader. Usually it is jobs, crime, substance abuse and other issues where genetics are usually not in that list. But we learned that, yes, the community first of all talks a lot about genetics, they may not use the kinds of jargon that we use. But they are interested and talk about it and they want to learn more about it. And it also allowed the community to develop structure to sustain the work in the area of genetics. And clearly, community information, coalitions were very critical in trying to establish structures so we could be able to continue that into the next phase of implementation. It has created among coalition members what we call social capital, that interconnectedness among organizations and individuals not only to address the genetic issues, but to address a host of other problems and issues impacting those communities. And it has strengthened, as a result, relationships among organizations and further collaboration in multiple other related areas.

Now in building partnership with communities, what is it a coalition community wants?

Well, first of all, we have learned that they want respect and acknowledgment of their expertise in terms of the culture value and culture norms that they're providing. They want equal partnership, including sharing of financial resources. They want active and meaningful participation in all aspects of the projects, from planning to implementation and evaluation. They want job opportunity, because interviewing and many other things that are involved in the research process create job opportunities and technical assistance to those organizations. They want to learn more about that. And then also the acknowledgment of the expertise the community has, and they want very strongly to have those kinds of acknowledgment, recognition, credibility. And finally, they also want ownership of the data. They want to make sure that the information goes back to the community in a simple fashion. The community can benefit. An organization could have that information available for multiple purposes.

So in conclusion, I could only add that there is not a specific way of conducting Community-Based Participatory Action Research. It depends on the community in question. Its leadership, the approaches taken in establishing partnerships and trust. But in terms of the Washington Heights, the process that we just described worked very nicely for us. Also, the focus on genetic education requires partnership with diverse audience at the local and national levels. If we have been successful because of partnership that was established and was strengthened and has continued to the next stage. It also requires long-term commitment from funders. Thank you.

PENNY KYLER: Thank you, Aida Giachello. Our next speaker is Maria. Maria.

MARY ZOQUIER-ESTEVEZ: Good afternoon, everyone. My name is Mary Zoquier-Estevez. I'm the former project coordinator for the Washington Heights GENE coalition. This is a network of organizations and community residents working together to improve access to quality culturally appropriate genetic information and services. Today, the coalition structure. We have a full-time project coordinator, five working communities, two consultants, and a conduit. One of the major goals of the coalition is to understand the needs of the community in the area of genetics. And for the very same reason, the coalition decided to engage in data collection process, as Aida mentioned through surveys and focus groups. The main goal of the survey and the focus group was to document people's knowledge in the area of genetics, as well as attitude and behavior. The coalition also wanted to document how much access the residents of the community had to services available there.

Lastly, the coalition also wanted to know what were the needs of the professionals in the community in the area of genetics. So there was a survey conducted. And members of the coalition, as well as the project coordinator and consultant, developed the survey and the document was approved by members at large. There were a total of 407 face-to-face interviews conducted by trained and bilingual interviewers from January through March 2002. Okay. As I mentioned, we also did focus groups. And with this focus group was with health care providers, Latino parents conducted in Spanish, Latino elderly conducted in

Spanish, African-Americans conducted in English. I would like to share the key findings of the survey. And I'd like to start by sharing some information characteristic of the respondents. There were 274 Latinos, 54 African-Americans, 79 non-Latino whites, 58% of all the respondents were male, 24% of all the respondents said that they were in poor health.

Again, this was self-reported. I'd like to note that. 30% of the Latinos and African-American versus 17% of non-Latinos white reported no regular source of health care. Next slide.

One of the questions that we asked participants of the survey was, if they had a condition. And the slide is showing the answer. And it was organized by their ethnicity. As you can see, 37.6% of Latinos said that they themselves had a condition. Followed by 31.5% African-American and 26.6 Latinos. There were a total of 34.6% of all the respondents said that they themselves had an inherited condition.

Next slide. As I mentioned before, we also wanted to know how much they knew about genetics. 46% of all the respondents said that they had a poor understanding of genetics. 21% had never heard of a genetic testing or screening. 30% when asked about genetic traits what was transmitted. Next slide. We wanted to know about their knowledge. And we had a series of statements. The first statement that we read to them, again, the surveys were not self-administered. We had trained people doing this. Never heard about genetics. And we can see that over 20% of Latinos said that that was true, that they had never heard about genetics. Followed by genetic diseases.

Next slide. Because we wanted to develop a location of material, we wanted to know what were the topics that we needed to concentrate on. As you can see, Latinos are interested and -- in most of the topics listed here. One topic that is more popular is genetics in general. Next slide. We also wanted to know if they had an intention of being part of the project or learning more about genetics. And although not a high percentage of the respondents showed an interest in being part of the coalition, most people wanted to learn more. And that's what we thought was really important. Next slide. As I mentioned before, we also conducted focus groups and two of the major themes that came out are here on this slide. And among the consumers who participated in the focus group, we noticed that they exhibit low levels of knowledge about genetic testing and genetic-related conditions. For example, I chose a quote from one of our focus group and the quote said, my uncle drank all his life. So his sperm count was low, so when his child was born slow, you know something that passed to the child because his father's gene or his grandfather's gene. We thought that quote was interesting and highlighted the needs in the area that the community had. We had a focus group with providers and what we learned was that providers expressed additional interest about learning about the community's culture.

For instance, in the area of documentation, religious beliefs, fear, and so forth. And the quote says, I think that religious and culture factors are part of a consideration, but don't think they are in the sum of it. What I find sometimes is a culture of the older generation saying either that they get a needle stuck or that you are going to puncture the baby. The other day, the woman was crying and she was 17 and she was crying and said, what's wrong. And the boyfriend said, I like the way my mother said, don't do this, or my

grandmother said, don't do that. So here we are, with all these things, you have them and you go home and discuss it with the parents or other family and right away you stop. And the quote highly illustrates some of the misconceptions and beliefs of the community and some of the frustration that providers encounter every day.

Well, after we had collected all the data, we took some action steps and developed a plan. And we identified major areas in which the community, the group, the coalition needed to focus on. And it's obvious that one of the major areas was community awareness and education. And the coalition engaged in a process of disseminating all the findings of the survey and focus groups in different communities that are a non-member of the coalition. And we went and shared information with people through a -- first thing we did was a press conference. And we invited members of the community to participate. And then we focused on target areas. Then we partnered with Doctor Victor, who conducted Genetics 101, sharing information with members of the community. We also presented at the last APHA annual meeting and we engaged in different dialogues in the community.

In total, there were over 10 education activities that happened from January to May of this year. We also partnered with one of the genetic counselors in the community and conducted a few dialogues on the importance of knowing family history. Again, this was done on a different community-based organizations. We invited a few speakers to the coalition meeting so that members continued to learn more about genetics. We will engage in another phase, and that would be providers in this area of genetics. And we

continue to promote the project in different venues, be it mail, email, and face-to-face meetings to recruit more members and continue with the efforts. Thank you.

PENNY KYLER: Thank you. Our next presenter is Doctor Othelia Washington Pryor representing the Washington GENE Project.

OTHELIA WASHINGTON PRYOR: Thank you. Good afternoon. What African-Americans need to know about genetics. The Michigan education needs evaluation demonstration project was an initiative -- In the African-American community --. (Please stand by.)

Our goals were to engage African-Americans -- (Please stand by) Our project had seven community-based organizations in the city of Flint and Lansing, Michigan. And this next slide shows the logos of the variety partners that we had. We had college students, we had several community-based organizations, consultants, we had two schools that were represented. We used two methods to conduct our needs assessment in the community. We used a qualitative process and we used a quantitative process. Our quantitative process was a MI GENE Project survey that was given to every member who came into our community dialogue process.

We had a total of 151 participants. The MI GENE survey had 50 Likert scaled and open-ended items and the demographic information which I'll refer to later, we also collected so we know who our participants are, and we also connected information on genetic and health sources of genetic information, access to genetic services, and we also assessed the genetic knowledge and attitudes and funding priorities of our constituents. In our

qualitative sessions there was a community dialogue process. The seven community-based organizations that we worked with hosted sustained conversations. When I say sustained, what I'm referring to is the fact that the community-based organizations recruited constituencies from their contacts, their organizations to come and talk with our facilitator for four sessions, an hour-and-a-half, or three consecutive sessions for a total of 22 sessions.

The next slide shows our community dialogue process. And as you can see, the project at the bottom, what we did, our process was a little bit different than the Washington Heights process. We established our organization around the community -- and all of the community-based organizations sent a representative on the community -- put a representative on the community advisory board. And they worked with the university representatives or research team to really guide the project. We initially conducted a focus group in the city of Flint and in the city of Lansing to determine what were the key issues that the community wanted to know about. From those focus groups, we conducted a -- we developed, rather, a dialogue guide. And the dialogue guide was to help mobilize the conversation or help really to facilitate the conversation of the three key topics. I will refer to those later.

So the community-based organizations recruited again, and this is for the same conversation, where we had individuals that came together for the three or the four-week sessions and talked about the three topics that came out of the focus group. From that process, we had the research and community advisory board develop a presentation for

the town hall meetings. Now our town hall meetings were very important. We had a town hall meetings in Flint and in Lansing. What the town hall meeting did, it give us the opportunity to present back to the community what they told us. And it also gave the community the opportunity to look at the data that we had collected and say, yes, this was accurate, no, it wasn't accurate, and this is how you need to change it. At our town hall meetings, both of the cities of Flint and Lansing, the participants said that we collected the data and we interpreted the data appropriately. And it summarized their feelings about the area of genetics and about access to genetics and genetics in general.

So we were really very pleased with that. And from that process, then we developed a community action plan. The next slide shows our demographic information from the 151 participants. 70% of our participants were female. The majority of our participants were between 31 and 40 years of age. You notice in our community, 85% of our participants had college experience. I think a lot of that had to do with the fact that we worked with college groups and 50% of our participants were working and 64% of our participants had private insurance. It's interesting to note that even though 85% of our participants had college degrees or had college experience, 46% of them did not have a formal instruction, did not have formal instruction in education. I found that quite interesting. One of the topics that came out of the focus group that we talked about in our sustained session, what does genetics mean. What does genetics mean? We asked that question to our participants. Some of the answers they said were the study of genes and chromosomes. Some of the people were concerned about the fact that genetics to them and family traits that are passed from one generation to the next, and there were a lot of people concerned

about the issue of genetic testing and 28% of our respondents said that when they thought of genetics, they thought of children's birth defects.

People mentioned environment, science, and culture. A quote from one of our sessions is solid. I think of my culture, where we come from, who we are, where we were born, and the race that we belong to. When our respondents were further discussing the issue of genetics, we talked about the impact of genetics on heredity and family traits. One of the issues that came up in our community was family health history. And the fact that in African-American individuals, especially older individuals will not discuss their family. And that was a problem for many of the people in our discussion group because they wanted to know the family health history and thought it was important. But the older generation who knew the ailments of the family and knew the diseases and the predispositions in the family lives just wouldn't talk about it.

They also discussed the fact of lifestyle and behavior risk and some of the genetic factors that are in your family. And the impact about what you do individually. 57% of the respondents reported an inherited disease and of those participants they talked about the benefits and the adverse impact of genomes on their families. The first quote is the first thing you think of is, oh my God, do I have it. Am I going to have it. Is it hereditary. The second quote, I have all my teeth, but you know my father had good teeth. I got a genetic trait that benefited me. So you could see that the respondents in our group realized that genes have adverse effect upon their health, but also could be a benefit. Of the individuals that said that they had genetic conditions in their family, 36% of the individuals related

diabetes as one of those conditions. 18% said high blood pressure, and you can see the percentages on the rest of the slide as to what our respondents thought.

In the area of genetic research, our respondents were very interested in the fact that 45% of our respondents said that they would participate, and they had a willingness to participate in research studies that were designed to help society better understand -----

This was interesting to us, because African-Americans are reluctant to be involved in -----

I think perhaps our participants were willing to participate in research because our research team was African-American and we were in their community working with people whom they had longstanding relationships. When we talked about the importance of genetics, they had more willingness to participate in studies. 89% asked funding questions. They said they had a willingness to fund research and they thought that it was important or very important for research to be funded. In exploring genes, 95% said that it is acceptable to my culture and my ethical beliefs to determine how genetic risk factors affect my health and the health of my children.

So this is another issue that we found surprising, because people were saying, I want to know about my risk factors and I want to know how they affect my health and the children's. One individual said, I guess I think about how will this testing be used, the results. Will everyone benefit? Or is it just for a select few? Another issue that was very important for our respondents was access, web access. When we asked the question about access, individuals said it was the knowledge about services and information and they thought it was very important that a central source of genetic information established

by the state should be set up where someone wants to know about genetics, you could go to this particular location that the state mandated and the state ran and you could find out. We also asked the question as where do you get your information. And this was a question that our individuals responded to multiple times. 57% said if they wanted information about health and health services, they would go to a health care provider. 38% said they would go to the Internet. And 31% said they would go to the health department.

In terms of educating our community about genetics, the health provider is important and it is important that he or she be involved in that process ----- About the availability of genetic services, this was another multiple response item. You see that the universities, medical centers and health care providers are the three key places where individuals will go to get genetic counseling services. It's interesting to note also that 13% said they didn't know where to go, and so even though most of ----- Got involved in the process were highly acknowledged. There is still a lack of understanding. Another issue that came up in terms of access was affordability. So even if you know ----- 73% of our individuals in the study said that genetic testing should be paid for by insurance. And they also wanted to assure that individuals had access to genetic counseling. And 71% of the individuals thought counseling should be paid for by insurance.

In terms of funding issues, insurance is looked at as a way to ensure that you had access. When we talked to them about the barriers that related to using genetic studies, individuals mentioned the location of the services, and issues of trust. Location of the services was important because 78% felt that the genetic services specialist should be

within the African-American community. This is almost ----- In communities of color and not combat the issues of trust ---- Historical nature of discrimination in our culture and also the historical nature of medical abuse that's been perpetrated on people of color. 72% were concerned because they thought genetic information might be a cause of discrimination. 81% ----- Because they wanted to make sure that the genetic information was private and so there should be privacy laws. 73% were concerned with test confidentiality.

The next quote was one that I had was a conversation that happened in one of our discussion groups and several individuals were involved. You can see the issue of miss trust and fear that's in this conversation. One person said there was a guy named -- there was a laugher, but it was a nervous laugh. Someone else said I've seen him. Then they looked at me and said this study is being funded by who. Even though I'm an African-American in an African-American community, they want today make sure that they were participating in something that would benefit our community. Also, an issue that came up in our focus groups that we used as a major topic for our discussion groups was what the word empowerment means. What does it mean to be empowered in the area of genetics? Community members thought empowerment meant equipping community members with resource and knowledge. Knowledge was seen as a protection or an empowerment to the people in the community.

They have to know what was there in order to access services. And 95% of the individuals wanted to ----- This was to make a decision. 99%, almost everyone in the study said

they wanted to know about genetic discoveries that could affect their health. So you see knowledge really plays into this. This would be empowerment if they knew this. They also wanted to know about the workplace environment, because individuals realize that given your genetic makeup - ----- What you're around in your environment in your workplace can affect your health. So they are concerned about this. Someone in our discussion group said I don't want everyone to be making the decision about my race and none of my race is at the table. So I would just feel more comfortable with more of us at the table. You could see that our community was involved with learning about genetics, so from that knowledge base, you could actually participate in a discussion, in policies about genetics that would impact -----

Our community developed a community action plan. We have six goals to that action plan. The first one is to assist experts in developing culturally appropriate material. There is material concerning genetics. But as was stated by our previous speaker, sometimes it's just available to us and it isn't a way that's readily access to the community. The people who it's intended for just find it something that isn't relevant. That's the first thing. This is something that we need to work on. We have not accomplished this, but we're working towards that goal. Goal two was hosting genetic education events. We've hosted several of them. We had an event at a school. We've had many speakers that have been involved in ----- Organizations and also in a solid fashion at the A.P.H.A. meeting and it's in Pennsylvania. We also want to assist experts in developing advocacy for our community members because our people want to be empowered.

One way to do this is to know how to go in and out of policy making decisions, how to be effective in making your voice heard. And our community members have already been involved with Genetic Alliance partners to develop an advocacy force that many of our members ----- Goal number four, we want to disseminate genetic information and materials for our community residents. As I said, we have been involved. And that's trying to inform our public through newspaper publications, through churches, through community meetings the findings of our study and what we need to do. Both five and six are really at the heart of everything that we want to do in our community because we recognize that our youth are our future. Five, we want to increase interest in youth to careers in genetic.

Goal six, increase youth's interest in science in general. As was quoted, a man didn't want people making decisions about our race. In order to get us at the table, we have to make sure that our youth know about science or know about genetics. If we can get more African-Americans involved in genetic ----- The final picture is one that I really just -- it just warms my heart I guess is the only way to say it. We have two African-American youths, a Doctor who is the director of the national research institute. We were at the Genetic Alliance conference last year, and he actually spent time working with African-Americans and really all of the students. The child and the young woman in the forefront is a woman of our community. She'll be going to the genetic ---- And the other young girl is from Philadelphia. But I think this is such an important picture.

The last quote in our presentation really summarizes the attitudes of our community for genetics education, genetic opportunities, information. This particular individual said, we need to get on the forefront, get involved with it, so that we can train and teach our culture what's going on so that we can reap the benefits of it. When as a group of people are we going to take the time to understand and learn? I want to be a part of it. We need to look at how we can have a voice in this and help people. I want to thank you.

PENNY KYLER: Thank you, Doctor. Our next speaker and last speaker is Doctor Teresa Doksum who has been part of the GENE Project as the evaluator. I'd also like to take a moment to ask you to start submitting your questions now so that the participants can respond to them. Thank you very much. Doctor Teresa Doksum.

TERESA DOKSUM: Good afternoon. My presentation will describe the purpose or the focus of our evaluation of the GENE Project. Our approach to evaluating the project and the methods we used, the results of the evaluation, major focus of this project was on partnership development, so that was a primary focus of the evaluation. And I'll discuss the outcomes of those partnerships aside from what you've already heard today, as well as the factors that were key to the success of developing the partnerships. I'll also talk about what we learned about genetics education initiatives that have both national and community components. Finally, I'll conclude with an assessment of whether the GENE Project achieved its goals and objectives. When we asked HRSA and March of Dimes what they want today get out of the evaluation, they said it should have three purposes.

First, they wanted it to describe the process or how they implemented the project. You'll recall that one of the goals of the project was for it to be replicated in other communities. So they needed a description of exactly how you go about implementing such a project. Second, they wanted it to -- the evaluation to assess how effective this approach was. Did they work? Did the methods work in achieving their goals? And the third purpose of the evaluation was to provide feedback to them for continuous improvement of the project. We used a participatory approach to evaluating the GENE Project in keeping in line with the participatory approach for implementing it. There is no right way to do a participatory evaluation because your approach will depend on how stakeholders are involved, the range of stakeholders involved and who controls the process.

In the case of GENE Project, we first made sure everyone was on the same page. So we gave a primer on evaluation and logic models to both the national and community partners. We worked with the partners to clarify the goals and objectives of the project, designed the evaluation, and developed logic models. We asked for feedback from partners on the research questions that guided the evaluation, the interview guides we used to collect the data, and on draft evaluation reports. We conducted case studies at the suggestion of two communities to determine whether single model for community engagement emerged versus assuming from the beginning that one model existed. Finally, that supplemented the information we were collecting as the national evaluators. How did we go about evaluating the project? We conducted phone and in-person interviews with national partners, with the key community partners which included the staff and consultants, members of the Washington Heights, Inwood coalition and the Michigan

advisory board, we conducted case studies of the community projects by visiting them every year, three years in a row. And we sat in on meetings and key phone calls. And we reviewed all major project documents.

Next slide. So what did our evaluation find in terms of the outcomes of partnerships? We found that as a result of the partnerships formed between the national and community partners, that partners increased their awareness and knowledge about each other's organizations. They learned a lot about genetics and genetics education needs of underserved communities, partners increased their sharing of resources with each other, such as their expertise in genetics, their expertise in outreach and advocacy. They shared publications, websites, grant opportunities. They collaborated with each other on other initiatives. I'll give you an example later in my presentation. They increased participation in each other's conferences, meetings and dissemination events, which were all of these were objectives related to the overall goal of developing partnerships for this project.

Next slide. So a lot of good things happened as a result of these partnerships, but it took a lot of hard work to develop these. The critical factors to developing partnerships included first and foremost, respect and trust. They also, for partnerships to work, they needed to have a shared commitment to genetics education in underserved communities, which would help keep them going when the going got rough. It was essential to have in-person contact, via project meetings and conferences. There was a lot of regular communication using multiple methods because different people preferred different methods of

communication. Consistency of representatives was also critical. And having representatives with shared cultural background.

Next slide. So we hope that you all will benefit from the lessons that we learned from the work of developing these partnerships. Some of the lessons learned include building relationship takes time, effort, and resources, such as staff and money to travel to in-person meetings, for example. Because just being at the same table is not always sufficient. Partnerships are more challenging if partners are chosen, rather than choosing each other, which was the case with the national partners in this project, who were chosen at the suggestion of HRSA. And this is especially difficult when there has been no prior relationship. And the roles and expectations need to be clearly defined up front and revisited as the project evolves, especially in a project such as this with lots of players and different levels at the national and community level.

Next slide. Other lessons learned included, you know, there's always going to be turnover in staff positions. And so changes in representatives and leadership require proactive transitions. To prevent having to start all over again in developing relationships between organizations. The partner relationships need to be -- partners need to feel that the relationship is mutually beneficial, that they're both going to get something out of the relationship and national and community participants not initially prepared to create partnerships which required the development of communication management and negotiation skills. Next slide. A unique aspect of this project was the formation of national and community partnerships. To form these partnerships, each organization needs to

identify a representative at the local level. They had a national representative participating in the GENE Project, but they also try to identify a local representative in each community. So what did we learn from this? We learned that the ideal community level representative from national organizations is a resident or someone who works in the community, is familiar with the national organization but also reports back to that national organization, has a shared cultural background with community members, shows respect for community members, has a consistent presence at meetings and activities, and has been given adequate time and resources to participate.

Next slide. The one example of a best practice related to these national community partnerships is what happened between the GENE Project and project Connect, which is another cooperative agreement between HRSA and the Genetic Alliance. And the Project Connect has goals that are similar to the GENE Project. So through Project Connect over a dozen members of both communities attended the annual Genetic Alliance conference last summer, many of whom received a scholarship to attend. And the Michigan, one of the Michigan GENE Project partners, Yvonne Lewis from a faith-based organization at Flint, worked with Genetic Alliance to develop a workshop on outreach and advocacy to make the conference more relevant for community members. And youth from both communities participated in the conference.

That also happened to be the external evaluator of project connect and in interviews with people from the communities, we found community members attended in part due to a relationship formed with the national representative of the Genetic Alliance to the GENE

Project. Many were already a little interested in genetics, but really had no idea what to expect from going to the conference. They made the leap of faith that they would still get something out of going and giving up their weekend for the conference due to the relationship that they had formed with this representative. The participants were highly satisfied with the knowledge they gained about genetics at the conference, learning more about the Genetic Alliance and learning about outreach and the networking opportunities were appreciated.

The conference presenters inspired and motivated the participants to do outreach related to genetics. And participants shared information and resources obtained at the conference with the community afterwards. Next slide. Overall, what did we learn about this type of genetics education initiative? We learning managing this is time intensive and you should achieve consensus earlier regarding the operational definition of participatory. Decision-making authority and what information is communicated and to whom. And assess the technical assistance needs and provide technical assistance to communities to build capacity and encourage ownership. Next slide. Other lessons learned are that you should expect the desire for influencing organizations to be two-way, the grantee or the community may also want to influence the funder and all partners need to perceive that the distribution of resources is equitable, appropriate to the task, and adequate.

And one unexpected outcome of this project was the formation of community to community partnerships. Each community wanted to get to know each other and share lessons learned as they were implementing their projects. So in conclusion, did the GENE

Project achieve its goals and objectives? We can say yes. HRSA and March of Dimes engaged the national and community partners successfully. The communities, as you heard, assessed the genetic education needs and assets using methods appropriate to each community and communities developed plans. The results and lessons learned from the project are being disseminated and which we hope will lead to replication in other communities. And the partners are beginning to participate in genetics policy, which was another goal of the project. And HRSA has funded March of Dimes to continue the effort to develop educational materials that are culturally appropriate and to expand the effort to two additional communities.

PENNY KYLER: Thank you, Teresa Doksum. We have a question from the audience. And I think each of the partners may want to answer this because there are different dissemination plans. The question is, please share your plans for dissemination of the overall project, particularly the evaluation findings. So we'll start with Doctor Teresa Doksum on that one.

TERESA DOKSUM: And March of Dimes can also address this, but the executive summary for our final report is currently on the website for the national newborn and we want to give that address. Okay. So Penny will be sending that address. And the full report should be available, I'd say, within a month. And we can send out a message to everyone who registered for this webcast when that is available. And there are other efforts to disseminate the project that the communities are involved with and the national partners to conferences and various agencies throughout the country. There have been several

dissemination events locally in each community. And if anybody else wants to add to it, that's fine.

PENNY KYLER: Do we have any other -- hello. Caller: Yes.

OTHELIA PRYOR: This is Doctor Othelia Pryor with the Michigan GENE Project. We have been involved in developing a website, this will not be an interactive website, but it will be ready within the next three to four weeks. It will be launched and individuals can go to our website and you can download our community action plan. You can see some of the presentations that we've given. We're going to be able to get a listing of the presentations that were given across the country concerning the GENE Project. We're continuing to work with schools in our area. We have some, just a lot of information about our project that we weren't able to share in the short webcast. But our community is very committed, very involved, still going forward with trying to -- we don't want genetics to be another area where we're disadvantaged.

PENNY KYLER: I just put out for all on the Marquis the website where the draft of the evaluation report is up as of today. And we expect eventually to have the final evaluation report up there, as well. Any other comments?

MARY ZOQUIER-ESTEVEZ: This is Mary Zoquier-Estevez from New York. We will continue to engage in dissemination of information locally doing downloads and

workshops. There's an effort to write an article for a professional journal and at the March of Dimes office. We will post all of our documents and our research.

TERESA DOKSUM: This is Teresa again, I'd like to add that when we post the full report, final report, the appendices will include the full reports from each community, their results of their needs assessment, as well as their local evaluations.

Also we have a couple of APA presentations in 2005 meetings, so we will continue to present the findings from this project.

OTHELIA PRYOR: This is Doctor Othelia Pryor from the Michigan GENE Project. Our project was featured at the Summit on May 2nd and the project received a director's award from the Department of Community Health. So we presented at that meeting and there must have been about 400 participants from genetic organizations, really from the Midwest.

PENNY KYLER: Right now, there are no other questions. So we would really like to thank you all for listening. If you do have other questions, feel free to email me at pkyler at HRSA.GOV. Thank you for your time and attention this afternoon.