

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
(DHHS)
ADVISORY COMMITTEE ON MINORITY HEALTH

TRANSCRIPT
OF
THE PUBLIC COMMENTS AND RECOMMENDATIONS PORTION
OF
THE DHHS ADVISORY COMMITTEE ON MINORITY HEALTH MEETING
OF
JULY 10, 2002

P-U-B-L-I-C H-E-A-R-I-N-G

CHAIRPERSON LOUIS STOKES: Anyone who would like to testify or to make comments before the committee this morning is requested to sign the sheet that they have at the door immediately, at the table immediately outside the door here. Will you do that for our records, please? We'd appreciate it.

Before we begin our comment period this morning, which is scheduled from 8:30 til noon, we have advertised that we will have a Public Comment Period this morning at which time members of the public are invited to make public comment to the Advisory Committee. We will recognize everyone that wants to speak. We'll give everyone an opportunity. If we have quite a number of persons who wish to testify, we may have to restrict the time in order to be able to accommodate everyone who wants to testify. But we'll try to be as lenient with each speaker as we can, because we welcome this opportunity to have you here and we appreciate the input that you will give to our committee.

Let me take just a moment and say that this committee is in existence by virtue of having been appointed by Secretary Donna Shalala, just prior to her departure as the Secretary. That selection was made by the Department of Health and Human Services and each of these persons who serve on this committee were chosen and appointed by her, prior to her departure from office. Of course, Secretary Thompson, under law has accepted the appointment of this committee and it is now the job of this committee to serve as Advisory Committee to the Secretary of Health and Human Services. Primarily, our function is to conduct meetings at which time we will consider legislation now pending before the Congress and other matters that are brought to our attention related to minority health. In that capacity, I might say that each of the individuals that Dr. Shalala appointed to this committee are individuals with extensive experience in the area of minority health and were selected because of their particular expertise in the area. I'm proud of the opportunity to serve as chairperson of this particular committee.

Our hearing today is the first time that we've had a longer session of public comment. Each meeting we have a period set aside at which time we accept public comment relative to our work. I think it might be nice, if you were to have the members of the committee introduce themselves to you this morning, so you might have some idea who they are and their backgrounds and things of that sort. As I said each of them has been appointed because of their own expertise in the area of minority health. Why don't I start, Ms. Satter, with you, if you'll take the time to tell us your name, and then tell us a little about yourself, and then each of the committee members will do the same.

DELIGHT SATTER: Good morning. My name is Delight Satter. I'm Okwan Quikitat from the Confederated Tribes of Grand Rounds. I work at UCLA Center for Health Policy Research, and I focus on American Indians/Alaska Natives both urban and rural

populations, but I also work with other populations of color, mostly in California.

ESTEVAN FLORES: Good morning. My name is Estevan Flores. I'm Executive Director of the Latino/Latina Research and Policy Center at the University of Colorado at Denver and a sociologist by training. I've served on national committees on immigrant and refugee rights, was a founding member of the Hispanic Health Coalition of Colorado, served 5 years on the Colorado Board of Health. Our center does work on health, education, and immigration, improving the quality of life for Latinos in the State of Colorado and beyond.

HO TRAN: Good morning. My name is Ho Tran and I work for the Illinois Department of Public Health, Center for Minority Health. I am the Special Assistant for Asian Affairs and also I administer the State Refugee Health Program. I am founder of the Asian Health Coalition of Illinois and also the Minority Health Association of Illinois.

TED MALA: Good morning. My name is Ted Mala. I'm Alaska Native. I work for South Central Foundation, the Alaska Native Medical Center. I'm the former State Commissioner of Health and Social Services for the State of Alaska and at present I'm the current President of the Association of American Indian Physicians.

YVETTE ROUBIDEAUX: Good morning. My name is Doctor Yvette Roubideaux and I'm a member of the Residency Tribe and I am faculty and Assistant Professor at the University of Arizona College of Public Health and College of Medicine. My work involves teaching, research, and program development in the area of diabetes and the American Indians and also Indian Health Policy. I'm the Chair of the National Diabetes Education Program American Indian Campaign, and a Past President of the Association of American Indian Physicians.

CLYDE ODEN, Jr.: Good morning. I am the Reverend Doctor Clyde W. Oden, Jr. I am senior pastor of Holy Trinity African Methodist Episcopal Church in Long Beach. For 22 years I served as president and CEO of the WATTS Health Foundation in Los Angeles and I'm also the Chairman Emeritus of the National Association of Urban Based HMOs.

SALVADOR BALCORTA: Buenos dias. I'm Salvador Balcorta, Chief Executive Officer of Centro de Salud Familiar La Fe, a community health and human services organization founded under social justice with a lead in social justice. I'm a Chicano from El Paso, Texas, and I'm also a national board member of National Council of La Raza and the person (inaudible) with Texas Affiliate Network of National Council of La Raza.

JOAN REEDE: Good morning. I'm Dr. Joan Reede, Dean for Diversity and Community Partnership at Harvard Medical School. My background is in pediatrics and child psychiatry and most of my work deals with workforce development and career development ranging from pre-college through graduate level and faculty level

programs involving students from largely Massachusetts but also from across the country.

ISAMU J. ABRAHAM: Good morning. My name is Isamu J. Abraham. I'm an Asian Pacific Islander from Commonwealth of the Northern Mariana Islands in SaiPan. I formerly was the Secretary of Public Health for the Commonwealth and I am now a Special Advisor for the Department of Public Health in the Commonwealth.

I consider myself representing a large Pacific Islander population a number of 500,000 people, including Guam, American Samoa, Federated States of Micronesia, and Republic of Marshall Islands.

ANTONIA VILLARRUEL: Good morning. My name is Antonia Villarruel. I'm an Associate Professor at the University of Michigan School of Nursing. I've worked at various capacities with Latino communities in Philadelphia, Detroit, and nationwide.

I'm Vice President of the National Coalition of Ethnic Minority Nursing Associations and my work focuses primarily on developing HIV prevention strategies for Latino youth and also African American.

NATHAN STINSON: I'm Nathan Stinson. I'm the Deputy Assistant Secretary for Minority Health and the Director of the Office of Minority Health in the Department of Health and Human Services.

CHAIRPERSON STOKES: I'm Louis Stokes, Chairperson of the Advisory Committee and I'm now retired after serving 15 terms in the United States Congress at which time I was either author of or involved in the major legislation that currently affects minorities and minority health.

With that we will begin our comment period. Again, I want to request that anyone who desires to make a public comment, please sign up at the desk right outside of the door to this hearing room. We'd appreciate that. For those who approach the mic to comment we'd appreciate it if you would first give us your name and your affiliation and then if you would make your comment. In the Federal Register, we advertised that all persons making comments would be given 3 minutes, and so, we're not going to try to limit you, but we will ask you to respect the fact that others are requesting time to appear this morning to testify. So, we'll ask you if you will please keep that in mind. With that, let me call upon our first person--Valda Boyd-Ford.

Good Morning.

VALDA BOYD-FORD: Good morning. My name is Valda Boyd-Ford and there is nothing quite like being first [laughter]. I'm from the University of Nebraska Medical Center and I'm the founder of the Center for Human Diversity in Omaha, Nebraska. I'm here to discuss strategies to increase the number of health care providers of color and to address the continuing and really disturbing problem of limited language access for patients of color. And, I'd like to just address it in two ways. We're starting to develop a program called the ELITE Program, which is

basically Entry into Language and Interpretation and Training and Education. And while it sounds at first like a program for interpreters, it is two pronged.

One it is to address the fact that in Omaha, Nebraska, we have in the past 10 years had a 272 percent increase in the Hispanic and Latino population, we have the largest population of Sudanese immigrants in the country, and our population is very diverse. I know you're quite surprised by that, because, everyone is not supposed to look like me who lives in Omaha, Nebraska. However, because of that, we've been caught by surprise, and we are very much unable to truly do a good job for folks. We know that people who do not speak English many times won't even try to access the system. And if they do, they're very frustrated because they do not receive, we know that they do not receive, the same level of care. So we have many trickle-down effects, whether we're talking about socioeconomics or bilanguage access. The point is many times there are strategies to increase the number of people going into health care professions. I am a registered nurse by education and training and have a masters in public health policy and analysis. So, I've been studying this problem basically for years and have lived in many countries and have seen where it works when I, as a registered nurse, don't know the language, the accommodations that are made to accommodate me speaking to the patients who are there. But we have not managed that here somehow, in this great country of ours.

So, my proposal basically is to look at other strategies that are less daunting, specifically to those people who may be disenfranchised. If I want to go to be a registered nurse and I'm a poor woman with say a child, I'm single with no support, you offer me a 4-year scholarship. I might not make it because I do not have support systems in place and the universities that are welcoming me in because it is the right thing to do, do not have the systems in place to understand, excuse me, my needs or my situation. So, we're looking at several things at the University of Nebraska Medical Center. One is developing a foundation to welcome people. Not just diversity training, but looking a policies, procedures, and the whole gamut. Secondly, to develop a program that looks at getting people who have language skills, who are bilingual and multilingual, and encouraging them to go into the health professions at entry level. Something that they can see that is an accomplishment, easily and readily, like nursing assistants, home health aides, and med techs so they're trained on the job or there is through our community college a 30-day to 90-day program. People can see the end in 90 days. Also to encourage that there be stipends given and other support systems like child care support and transportation. After that, those who qualify will then be given training as medical language interpreters.

Another disturbing trend is the confluence of 1-week

medical language interpreter programs that are popping up that people find acceptable that I would never want anyone interpreting to me about my coronary artery bypass graft who has had 1 week of throw it on the wall, catch it if you can, medical interpretation training. None of us would accept that, but we expect new immigrants to accept that. So, we want to first of all train people to be nursing assistants or whatever entry-level health profession and expose them to the careers. Because many people don't know what a nuclear imaging technologist is. It's not something that they know about. And I speak to this from experience, because I started off as a nursing assistant. I was offered a scholarship at Duke University, but could not go because I could not afford the extras. So I went to a 2-year program, 10 years later got my bachelor's, 5 years later got another bachelor's, and 5 years later etcetera, etcetera.

Sometimes people criticize this idea to say why put folks who are down in low-income positions, but it's just to get them in. Usually hospitals and other health care organizations are quite willing to finance your continuation or to give you time to go to school and all those other supports. Just to get you in, the pay is usually 8 to 14 dollars an hour so there is no shame to work that game. A lot of people who have bachelor's degrees aren't there yet. So, once that is finished to have an interpreter training program that would allow for a full month of classroom training after you understand some of the workings of the health care system. Then, the benefit to the employee, is they have a multipurpose person and also to make sure they don't get beat up with dual jobs, so that you are expected to interpret full time and do your job as a nursing assistant full time. To do the continuation we are asking hospitals and other health care organizations to pay for the person when they are finished to put that back in the pool to continue the stipend fund so that everyone can continue to go. Thank you.

CHAIRPERSON STOKES: Thank you very much Ms. Boyd-Ford.

I've just been advised that we have an extremely large number of individuals who have now signed in and want the opportunity to testify. As I said earlier, we want to try and accommodate everyone. I think, out of respect for all of those who want and deserve time, we are going to have to observe a time limit. Since we did advertise that you'd have 3 minutes, I'm going to ask everyone to confine their comments to 3 minutes, so that we can get to everyone that does want to testify. Now 3 minutes may or may not seem like a long time to you. I served in the United States Congress where no matter how important the legislation was, there were occasions where we had 1 minute. No matter how earth-shaking I thought my speech was, I had 1 minute to get it out, and after that the Speaker cut me off. So I would like for us to operate in a way where I don't have to cut any one off. And if you will cooperate with me--

We are going to wait a moment, so we can get more

chairs in and accommodate more people. We had no idea that we would be this popular this morning. We're delighted to see the number of people who want to get in to the hearing. We're now exploring the possibility of being able to move to a room that can give us greater accommodation. So, we'll let you know as soon as we find out. Meanwhile, I hope that you, everyone, will kind of go along with fact that we had no idea that we'd have this type of turn out this morning. One of the persons who will testify asked if I would at the 2-minute time, give them some indication that they have 1 more minute. So, I will do some kind of banging here to let you know you have 1 more minute and that will help if you will wrap up. So, if we can, at this point let's try and resume. Our next witness is India Ornelas.

INDIA ORNELAS: Good morning and thank you for your interest in border health. I'm India Ornelas a border health prevention specialist from the Centers for Disease Control and Prevention, currently working at the California Office of Binational Border Health, one of the four border health offices in each U.S. State along the U.S./Mexico border. As part of the California Department of Health Services, our mission is to protect and improve the health, well-being, and quality of life of California's border and binational communities. We're facilitating cooperation with Mexican health professionals and officials. We have completed our first two annual border health status reports. I will present the highlights and recommendations of the reports to you today. I have also submitted copies for your review.

Drawing upon the national health objectives outlined in Healthy People 2010, the U.S./Mexico Border Health Commission, the National Center for Health Statistics, and Mexican health officials identified 25 of the most important objectives for the distinct needs and concerns of the border. Nineteen of these objectives are similar to Mexico's national health objectives and together these are known as the Healthy Border 2010 Objectives. Our office conducted a review of how California's border communities compare for these 25 indicators. We found that lack of access to health care, high rates of tuberculosis and HIV/AIDS are our greatest challenges, but especially in Latino communities. And in our more rural border communities, asthma and motor vehicle death rates are at least two times the rates found in the rest of the State.

We also reviewed legislation and policies related to collaborating with Mexico for public health and surveyed health professionals in the border region about their challenges to binational collaboration. From this review and the feedback from our colleagues, we developed recommendations for improving the health of California's communities. We believe many of these recommendations are applicable to other border States as well. Number 1: Establish bi-State (in this case between California and Baja, California) strategic plans and offices with dedicated

staff for improving the health of the region.

Number 2: Identify efficient mechanisms for the exchange of resources between the U.S. and Mexican agencies including equipment, specimens, training, and information technology.

Number 3: Establish detailed protocols at the Federal and State levels for exchanging data with Mexican counterparts that can be used for disease control, planning, and implementing public health interventions in border communities.

Number 4: Increase the number of culturally and linguistically competent health professionals on the border. This includes hiring bilingual/bicultural staff, funds, and support for language training, as well as training on the Mexican health system and business protocols.

In a recent joint statement, the Presidents of U.S. and Mexico stated "The events of September 11th underscore more than ever the importance of the U.S./Mexico relationship as partners and neighbors. It is a high national priority of both countries to continue building on that cooperation." Our hope is that this spirit of collaboration both within the U.S. and with Mexico will lead to improved health in our shared communities. Thank you.

CHAIRPERSON STOKES: Thank you Ms. Ornelas. Our next witness is Ms. Molly Kealy.

MOLLY KEALY: Good morning. I don't do this very well.

I am a labor and delivery nurse in Anne Arundel Medical Center in Annapolis, Maryland and I'm pleased to give my comments this morning on behalf of my nursing association--the Association of Women's Health, Obstetrics, and Neonatal Nurses. We're an organization that's comprised of 22,000 health care professionals and we promote the well-being of women and newborns. And I'm going to read from my notes. We'd like to touch briefly on two areas this morning, and that is maternal mortality and cultural competent care.

The United States ranks 20th out of 49 developed countries in the annual number of maternal deaths. In the United States about 1,000 women will die each year from pregnancy-related illnesses or conditions. Two or three lives are lost each day due to pregnancy-related mortality. One of the alarming aspects of the maternal mortality rate in this country is the highly disproportionate rate at which minorities are affected. We know that pregnancy-related mortality ratios continue to be three to four times higher for black women than for white women, and black women have a higher risk than white women of dying from every pregnancy-related cause of death including hemorrhage, pregnancy-induced hypertension, and embolism. Other populations suffer disproportionately for various disorders. For example, the leading cause of pregnancy-related death for Hispanic women is pregnancy-induced hypertension. Native Americans are at greater risk for alcohol abuse during their pregnancy. Part of the disparity problem is unequal access to prenatal care and health care coverage. According to a recent Centers for Disease

article, infant mortality rates were higher for mothers who began prenatal care late or not at all. Prenatal care and preconception counseling can be immensely helpful as they allow for early identification of risk, advice on consuming folic acid to prevent birth defects, initiation of appropriate and effective health promotion interventions, education stressing the advantages of planned pregnancy, and the importance of the earliest weeks of pregnancy. Minorities are less likely to have timely, quality prenatal care. And, late or no prenatal care is associated with lower birth weights and a higher rate of preterm births. My nursing organization recognizes the importance of addressing disparities in the delivery of health care and encourages the use of targeted related research and community-based strategies to improve maternal and infant mortality and morbidity in diverse populations. We would also like to emphasize the importance of providing grants to health care providers working in the field as well as to facilities that are educating future health care professionals to support education offerings that will promote culturally proficient services to pregnant women in diverse communities.

Another piece of the health disparities puzzle is providing culturally appropriate care that not only provides access to the health care system and basic standard medical and nursing care, but for example, in our specialty, maximizes the birth experience according to cultural expectations and norms for optimal care in the perinatal period. Health care providers should take into account different world views that surround the childbirth experience including the knowledge of cultural issues, barriers, and perspectives that influence care during preconception, labor and delivery, and postpartum phases. Providing culturally competent care commands that health care professionals demonstrate an awareness and acceptance of, as well as respect for, cultural, religious norms, patterns, beliefs, and differences. While support of a nursing delivery model that integrates culturally competent care is critical to quality health care in all specialties and practice setting, this is especially important in efforts to improve birth outcomes.

[One-minute warning] Thank you. I'll be the first for that, huh? Birth is a richly cultural experience that is best supported by a nurse workforce that represents the ethnic diversity of the population served and has a comprehensive understanding of the impact of cultural components on the outcome and satisfaction of the birth experience. Achieving cultural competence should be an integrated part of training for all health care professionals. We cannot afford to wait for the next generation of health care providers to create a health care plan that will be comfortable for all Americans. There's evidence to show that minority health care professionals are more likely to provide care to their own racial and ethnic population, yet there remains a dearth of providers that reflect the changing

demographics of the U.S. population. Racial/ethnic minorities comprise about 12.3 percent of the current registered nurses compared to about 28 percent in the U.S. population. It is imperative that we look at incorporating cultural competence in health professions curricula as we actively seek new ways to open the doors of the profession to racial and ethnic minorities. We encourage the Advisory Board to continue efforts to diversify the health care workforce in the U.S. and welcome the opportunity to work toward diversification, especially related to increased minority representation in special areas of nursing such as labor and delivery. Thank you.

CHAIRPERSON STOKES: Thank you. We are going to be able to open up this room here, adjacent to us, providing this additional room to accommodate those who want to be with us this morning. We will now proceed to our next witness. Vernellia Randall? University of Dayton.

VERNELLIA RANDALL: My name is Vernellia Randall. I'm a Professor of Law at the University of Dayton. I teach race and racism in the law and health care law. I'm also a nurse and practiced in Alaska and Seattle for 15 years. I come to this, I say that, because I want to give some context. Ten years ago, I wrote an article Racist Health Care, a Law Review Article. Nothing has changed. The discrimination in health care is rampant. While we focus on the disparities at the community level, and that's important, we have to eliminate discrimination.

That Title VI is inadequate is well documented. My point is that it cannot be made adequate. Health care is a unique situation. Individuals do not know when they have been discriminated against, cannot know when they have been discriminated against and so cannot bring suits of discrimination. We need, like housing, like finance, like education, we need a specific health care anti-discrimination law. That law would allow testers to bring suits. That law would require Medicaid, Medicare, and any institution that accepts financial assistance to collect data on not only providers, but treatments and facilities, and would allow it to be collected in a way in which researchers and others could easily demonstrate disparity impact discrimination. That law would allow for disparity impact discrimination based on statistics. The fact that we do not want to acknowledge the bias and stereotypes that are the bases for discrimination in terms of the law is a real problem and we have to correct that in a specific law. We would also allow for huge fines, because I believe that individual law suits will not be enough so that a Federal agency or State agency should be responsible for determining whether or not institutions and providers are discriminating, and then laying huge fines on them for disparity impact discrimination. We, thank you, I talk so loud, I didn't even hear that. OK. I think I've said all of the main points that I wanted to say. I will be writing up a short piece to give

to you. I just want us not to lose sight of the discrimination that occurs in health care and the fact that Title VI cannot be fixed. And so, if we're looking at Title VI as a way to eliminate discrimination, we are going to be in trouble in another 10 years. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Randall. The next person is Luis Guevera.

LUIS GUEVERA: Good morning. My name is Luis Guevera. I work at White Memorial Medical Center in East Los Angeles, in the Family Practice Residency Program. I'm a clinical psychologist there and I serve as the manager of cross-cultural training and I just want to thank the Advisory Committee for giving us this opportunity. To let you know, at White Memorial we work with mostly Latino residents there. Over 90 percent are Latino. Many of them are recent immigrants. So everything that comes along with that, comes to our patient population, many of the diseases (diabetes, hypertension, cardiovascular disease) and also as well everything that comes along with being in a poverty-stricken community. So, with that, what we try to do at White Memorial, I'd like to share some of our successes in the hopes that maybe others can help, can also exemplify possibilities to provide examples of how other, excuse me, I'm not used to doing this either, of how other medical education programs can follow some of this.

We believe in providing community-oriented primary care as a curriculum, so that we can train physicians to work with people. In our Family Health Center we have mostly 90 percent Medicaid recipients, uninsured, and not only disadvantaged, and we help prepare physicians to work with this, as well as, whether they are Latino or not, whether our physicians are Latino or not, we prepare them to work with this population. And, long before they get to our program we work with them in the sense of, we work with pipeline programs, the California Minority Medical Educational and Training Program is a perfect example of that. That works with K through 12 schools who have, with students who have an interest in health careers. Long before they get to us we also have a significant recruitment process, and just to show most, 70 percent of our graduates come from under-represented communities.

So, in our work we just wanted to, some key recommendations that we wanted to stress today is to provide coordination for existing Federal, State, local, and also private sector (to note our hospital is a private sector and I think sometimes public advocates forget about public sector providers in this work). We need to coordinate these efforts for under-represented minority applicant pools. We need to develop an outcome study for under-represented minority college students who profess an interest in health careers, but then never finish. We need to find out why that's happening. We need to provide academic enrichment programs, applicant and reapplicant advising,

and accurate career counseling for UMR students. We need to engage UMR physicians in medical school admissions. Just a couple more. We need to strengthen MIMA-type programs. And we also need to expand minority-oriented medical school size such as historically black colleges and universities, minority serving institutions such as Julius E. Lee, and we also need to expand State and Federal programs such as the California Shortage Area Medical Matching Program as well as the California Loan Repayment Program. Those are some of the specific examples. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you Mr. Guevera. Also, I might say, in view of the time limitation here, we would be more than pleased to have anyone who is testifying here today feel free to submit to the Committee your written testimony and any documents that you'd like for us to take into consideration.

AUDIENCE MEMBER: We'd definitely like to know, will we ever know what your thoughts or your comments are to all of ours. In other words, what happens?

CHAIRPERSON STOKES: Well, what the Committee would like to do is to take advantage of the testimony you are giving us today. As I said earlier each of these individuals are very much aware of the areas in which you are testifying and if you have anything you'd like to submit in writing to us, we'll certainly take it into account. And then in our deliberations, we will certainly take note of what has been testified to here today and take it into consideration.

AUDIENCE MEMBER: And this will be demonstrated in what form? Will it be published in a newsletter or in the Federal Register?

CHAIRPERSON STOKES: No I think our eventual, the eventual work of the Committee will be in a form of recommendations made to the Secretary of Health and Human Services and everything that we had the advantage of (you are not the only ones who have testified before us, in all of our meetings we have people testifying before us and then) we take that into consideration in terms of our deliberations working towards our final document in which we make recommendations to the Secretary of Health and Human Services. So your input here today will be part of that process. Thank you. Mr. Michael Bird?

MICHAEL BIRD: Good morning, Mr. Chairman and Committee members. Thank you very much for this opportunity and your dedication and commitment, which you've demonstrated this morning by holding this hearing. I am from Santo Domingo in San Juan Pablo in New Mexico. I'm American Indian. My people have been in New Mexico anywhere from 10 to 40,000 years so welcome to my country. [Laughter and applause]

I am the Immediate Past President of the American Public Health Association, the largest and oldest association of public health workers in the world. It took 127-some years for

an American Indian to become president of that association [applause]. Thank you. So I am blessed with a real opportunity to speak out on behalf of native people and all people. Because, the fact of the matter is, in this country, I think more and more people are beginning to understand what it's like to be an Indian, and we need all the allies and friends that we possible can muster. So, welcome to the tribe. I need not go into the data, the statistics that reflect our condition, our shared disparities. But, I'm actually here to just mention something specific to American Indians at this particular point.

In 1970, President Nixon delivered the following statement to Congress: **A**The first Americans, the Indians, are the most deprived, most isolated minority group in our nation on virtually every scale of measurement (employment, income, education, health) the condition of the Indian ranks at the bottom. This condition is the heritage of centuries of injustice. From the time of first contact with European settlers, American Indians have been brutalized, deprived of their ancestral lands, and denied the opportunity to control their own destiny. @

Disparities are a reality for too many Americans in this country today. One example of an effort that I have been involved with has been with SHIRE Summit Health Institute for Research and Education, 2 or 3 years ago it was. And, a number of us, 75 organizations were involved in multi-cultural/multi-ethnic coalition building. And, we felt that it was important for us to come together as people of color, as people representing multicultural heritage and ancestry to begin to formulate our own approach to dealing with disparities in this nation. We felt that we have the skill, the ability, and the knowledge to in fact begin to address those issues in this Nation. We also felt that we could come together based on a spiritual understanding of the reality and that drawing on the strengths of a shared spirituality reality, which has sustained us for hundreds of years. And, I am happy to say we'll be presenting on Thursday morning, any of you who might be interested in learning something about that effort. I also would say in closing, I want to share with you some ancient knowledge and wisdom coming from Chief Seattle, and here's what he had to say, and I think it's relevant. It was relevant hundreds of years ago and even more relevant today. He said: **A**Will you teach your children what we have taught our children that the earth is our mother? What befalls the earth befalls all sons of the earth. This we know. The earth does not belong to man, man belongs to the earth. All things are connected like the blood that unites us all. Man does not weave the web of life, he's merely a strand in it. Whatever he does to the web, he does to himself. Thank you very much [applause].

CHAIRPERSON STOKES: Thank you very much Mr. Bird. Franklin Zavala-Velez? [Comments not audible] Professor Silva

Jurich.

SILVA JURICH: Thank you. My name is Silva Jurich and I'm the founder of a community clinic in San Diego called La Maestra Family Clinic. I would like to make three points: The first one is that I would love to see published in the Federal Register whenever agencies announce grants for the education of nurses and physicians for there to be a set-aside for community-based organizations to provide training for certified positions such as medical assistant. I believe this would really increase the pool at the bottom of the career ladder for, and then promote increased access and eliminate health disparities. The second point I would like to make is that I would like to draw the attention of the Committee and everyone else here to the fact that job training monies, Federal job training monies, under the JTPA (the Job Training Partnership Act) are funneled through certain regional organizations. And these organizations used to be called ~~A~~The PICS~~@~~ (the Private Industry Council) now they are called ~~A~~The Workforce Partnership.~~@~~ The Workforce Partnership tends to have a pattern of funding the same people over and over again and because of, partially because of that, their entry level requirements are too high for our immigrants and refugees to enter people with limited English proficiency. In other words, to be a CNA, you have to have a 10th grade reading level and you have to have an American high school certificate, which is hard for my Somali nurse to get. Therefore, if there's any kind of collaboration that can be made with the JTPA to influence that these new populations be included and that the entry-level requirements be changed, I believe that we would have a chance to educate more of our people. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you very much Professor Jurich. Dr. M. Chris Gibbons. Good morning.

M. CHRIS GIBBONS: Good morning. My name is Dr. Gibbons, and I am currently the Associate Director of the Johns Hopkins Urban Health Institute in Baltimore, Maryland. It is our position that all recommendations of this Committee, with the establishing of an Office of Urban Health, would significantly complement efforts to improve minority health in the United States. As you know minority populations are disproportionately represented in urban central cities. According to the American College of Physicians, one of the Nation's oldest and largest physician organization in this country, a position paper which they wrote in 1996 ~~A~~the U.S. health care system is not functional-- [tape ends] it cannot be fixed and entirely new models of care are needed within the central cities.~~@~~ The ACP has taken this position because 20 percent of the U.S. population lives in or near our 100 largest cities in the U.S. And, this is also where the majority of the Nation's largest, best, and oldest teaching hospitals and medical establishments are located. And, if these medical establishments are threatened, more than one out of five citizens in this country are threatened.

So, this is not just an urban or minority problem, this is a U.S. health care system problem. While urban problems like poverty, access, and aggregate utilization patterns are similar to rural areas and other areas in this country, the concentrations of these problems require focused, coordinated, systematic, and ongoing leadership support and commitment. We believe that an Office of Urban Health could lend this support, leadership, and commitment to your efforts and improve the health of all racial and ethnic minority citizens of these United States. Thank you [applause].

CHAIRPERSON STOKES: Thank you very much Dr. Gibbons. We appreciate your testimony. Suki Terada Ports.

SUKI TERADA PORTS: Good morning. Thank you for this opportunity for providing this testimony. I'd like to first just give a little context for my city, which is New York City. About 2 years ago, three white elderly Jewish women died of a disease.

Instantly (and for New York City that's pretty amazing) within 6 months, there were posters and brochures in over 40 languages and the city was sprayed numerous times with helicopters going across the entire city much to the dismay of people with strollers and walking dogs and so forth. And the green grocers were never told to bring their vegetables in. However, these three women instituted this massive reaction and it was the West Nile Virus, which so panicked the city. So the mosquito was chased in this very rapid succession. It will now be almost a year ago that over 3,000 people were killed at the Twin Towers. Those survivors will have millions of dollars of help for the families. They will have health care. They will have job assistance. The children will have college scholarships and most importantly, they will have mental health care for the results of the loss of a member of the family.

Now, since 1981, 120,783 people of whom 73,945 are dead from HIV and AIDS. Eighty-seven percent are women of color, 69 percent men of color, 73 percent total people of color for a total of 89,503 compared to the 3 and the 3,000. Those survivors will have no guarantee or no plan for the orphans. They will have no money. They will have no health care, except for what they have. In 1987, 52 percent were men of color and 84 percent were women of color. We have not had a change. This is not a new disease. This is not something new facing New York City.

In the year 2000, as a result of the partnership, from June to December of 2000 the results show that 88 percent of the new cases of HIV were people of color and 81 percent of the new AIDS cases were people of color, for a total of over 5,000 people. And, I urge you, this is not something (which some people have gone over to Barcelona and the United States Department of Health has mentioned) black and Hispanic. It is not just black and Hispanic. It includes Asian and American Indian and Pacific Islander. And it includes a lot of poor people. And there is an urgency. It is killing our communities. And, I ask you to treat

this as an urgency. It is seriously decimating our communities and it is really a basis of major racism and systemic change that we need. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Terada Ports. The next witness J.R. Fernandez-Peña. Do I pronounce--

JOSÉ RAMON FERNANDEZ-PEÑA: That's alright. Good morning my name is José Ramon Fernandez-Peña and I am from California. I work with [inaudible] University at City College, San Francisco. I am Director of an initiative called the Welcome Back Program. The mission of the Welcome Back Program is to build a bridge between the pool of immigrant health professionals residing in California right now and the need for culturally and linguistically competent health services in underserved, immigrant communities in California. Our goal is to contribute to the diversification of the health workforce for it to better reflect the population of the State. We started our services in February 2002 and we have located thus far over 1200 participants from over 76 countries in our 3 locations in San Francisco, Los Angeles, and San Diego. The people we have identified are primarily from Latin America, mostly Mexico, Nicaragua, El Salvador, Peru, but also from the Philippines, from China, from Russia, and from many other countries. We have physicians, dentists, nurses, social workers, psychologists, physical therapists, radiation therapists, you name it. Our services are delivered through an educational case manager who meets with the participants to understand their needs and situation and to prepare an educational plan including realistic goals that will bring people back into a health workforce along two possible tracts, leadership or direct services. We understand that it is not often possible to reenter the health workforce at the same level the person had in the country of origin. So, we offer additional training for them to be able to reenter the health workforce in some capacity, but bringing with them their skills, their culture, their language, and their knowledge of the communities.

The point I want to make is that in these difficult political times, it is important to remember that immigrants can and do make important contributions to society. It is important that we don't lose track of this fact and that we continue to leave doors open for these contributions to be made. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you very much. Mr. Jerome Hanley?

JEROME HANLEY: Good morning. My name is Dr. Jerome Hanley, Professor at the University of South Carolina Medical School, Department of Neuropsychiatry and Behavioral Sciences and one of the directors of the South Carolina Center for Innovation in Public Mental Health. I appreciate the opportunity to be before you this morning. Now I have some (I hope) very brief comments to make.

Every day the fate of African people in this country are affected by four factors. Those factors are economics, politics, history, and race. Racism is going nowhere, and we have minimal ability to impact the other three. Until we're able to do so, the issue of health disparities is going absolutely nowhere. We gather data, but we rarely use it. And data does not drive policy. Data does not drive policy. It also oftentimes does not drive practice. I come from a behavioral healthcare background. And with that we still do not see the use of ethnopharmacology being used. I encounter residents that haven't even heard of the concept of ethnopharmacology. So I guess they will not, until they get sued. And, once they get sued, then they will become enlightened very quickly.

I happened to be in South Africa during an international conference on AIDS. Not one time was the issue of culture raised in that conference. In the absence of knowledge of culture, there will be no prevention. In the absence of knowledge of culture there will be no prevention. [Applause] In the initial training, I worked a great deal with the African residents and I developed a seminar entitled **A**Healing the Hidden Wounds,[@] and only African residents are permitted in that particular seminar. Because the educational process can be so damaging that by the time they complete their work, they are of very little value to the community from which they came. [Applause] Many, in fact, don't even remember the community that they came from, because there was such an effort on the part of their non-African faculty to make them fit into their likeness, that they can't even go back and understand the very issues from which they came from, which defeats the purpose of having African faculty members. I want to end with an African proverb. It is a Tsutu proverb from South Africa and it states very simply: **A**Do not die like a snake with your mouth open saying nothing. Do not die like a snake with your mouth saying nothing.[@] It is time for us to stop being comfortable and be about the business the creator put us here to do. [Applause]

CHAIRPERSON STOKES: Thank you Dr. Hanley. Next witness Gregory Seany-Ariano.

GREGORY SEANY-ARIANO: I work in AIDS services in Asian communities in Philadelphia. I'm also a student at Temple University's Multicultural Institute. I didn't really have anything prepared to say except for looking through the workshops, I was just surprised that there was no mention of LGBT issues. And, I feel that, well I know that in multiculturalism LGBT issues are now considered part of the rainbow, and I just feel that if you're gonna have a conference like this, you need to be addressing the LGBT issues. If you're going to expect your department to really address the devastating, the issues that are devastating communities of color, without openly including sexual minorities in your dialogue, you're not gonna be reaching a lot of people. And, I guess, you know, when you put your curriculum

together, if you could just include transgender issues, other things like that. And then, I guess to sum up, I like the last quote: **A**In the absence of the knowledge of culture, there will be no prevention.@ [Applause]

CHAIRPERSON STOKES: Thank you. Ms. Seany-Ariano. Next is Martin Ornelas-Quintero. Good morning.

MARTIN ORNELAS-QUINTERO: Buenos dias my name is Martin Ornelas-Quintero and I'm the Executive Director of LLEGO, which is the National Latino and Latina Lesbian, Gay, Bisexual, and Transgender Organization. So I think that the creator had a order that I was to come here, because I am gonna speak about homophobia specifically. The impact of homophobia on our communities, I'll speak from the Latino perspective, and with the knowledge that it can also apply to other ethnic/racial groups. It's so insidious that we don't even see it anymore. It's so insidious that it comes out in every daily interaction. It's so insidious that at times when we have gatherings like this, that many of us, I look around the room, we've been in similar rooms before, where we together advocate for ethnic/racial communities= inclusion. And, now I ask you, as members of the Advisory Committee to also demand inclusion of lesbian, gay, bisexual, and transgender ethnic/racial communities.

I can only tell you stories of how difficult it is for many in our communities, compounded by the same factors that all of us are already compounded. As an immigrant, I face the same challenges that many other immigrants do, whether its my health status, my immigration status, my age, the undereducation, the lack of access to competent services. Imagine going to a physician and being a Latina lesbian where they continue asking about your sexual history. Where they continue asking questions as if your partner is a man. It requires for you to be in such a comfort zone, a comfortable place, to say **A**that's not me.@ We know for marginalized communities, whether were immigrants, we know that oftentimes that compromises the type of service we get, that compromises our ability to stand up for ourselves. And, that is why us as advocates who have voice, are able to come into positions like this and say **A**we demand this type of quality, competent services.@

So, in closing, I implore you, while I have a minute so I don't have to close now [laughter]. But I do ask you in your recommendation, it is not a coincidence that there are no discussions about lesbian, gay, bisexual, and transgender issues in this conference. It didn't just happen, it was purposefully taken out of the program. That's a piece of information that you need to know. We were part of a coalition that we sit on the Executive Committee of the National Coalition for Lesbian, Gay, Bisexual, and Transgender Health. Right, and in that forum, which is largely a white context of us as communities of color fight to have our right place at the table. I implore you, do

not make us fight for our place at the table. Open the doors and welcome us in. Because we'll be demanded, we need it, and we're willing to work with you and go the long haul in that struggle. We will be submitting formal comments, and again I thank you for the opportunity. [Applause]

CHAIRPERSON STOKES: Thank you very much Mr. Quintero. Erin Moran?

ERIN MORAN: Good morning. Thank you for having us here. I appreciate this opportunity to address you. My name is Erin Moran and I'm an employment coordinator at La Maestra Family Clinic in San Diego. Our clinic is located in the border region and we serve a wide variety of minorities and immigrants in our area. In particular, we serve over 40,000 new immigrants. In particular, African refugees from Sudan, Somalia, and Ethiopia. And, what I came here to ask you this morning, is to consider in your definition of minorities to include the term **Anew immigrant.**@ This is something of concern and importance to our organization and to many in California and the border region because it has long-term implications on what programs are funded and what is considered under the term **Aminority.**@

We have a training program, which is designed to train new immigrants for work in the health care field. And, I did hear comments earlier this morning regarding the need for these people to be working in the health care field because of the need for interpretation, the need for cultural understanding, and cross-cultural issues that come with health care. And, we are able to address this only in so much as that there is understanding that there is this population that needs to have special consideration. And, what it does indicate is, when immigrants first arrive in this country, they do not have the GED. They do not have the ability to graduate from high school. And, when they then join into training programs like ours, they're excluded from long-term training programs such as the LPN and nursing association training programs. And, in terms of health care, it also excludes them from being included in evaluations of their health needs assessment, because they are lumped into the same category as minorities, which is inappropriate because they come with different health needs and different health concerns. So, just my brief comment today is to consider including that in your term. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Moran. Our next person will be Marguerite Ro.

MARGUERITE RO: Hi. My name is Marguerite Ro. I'm an Assistant Professor at Columbia School of Dental Neurosurgery as well as the School of Public Health. I have two quick categories to address and I will be more than happy to provide the Committee with other supporting documents. The first deals with the recruitment of a minority workforce and the second is supporting research conducted through academic and nonacademic institutions or agencies. The first is the one issue I wanted to bring up is

the oral health workforce because that is an area that we often forget when we talk about health. We generally think of health as just physical, but we also need to remember too, that the mouth is part of the body. I ask that HHS look at supporting demonstrations that encourage the recruitment and training of minority oral health providers in research. There are several foundations who are currently supporting these efforts. These efforts need to be also replicated through the Federal agencies that support demonstrations in research.

The second piece is looking at health policy research that explores the responsibility of private and public institutions to provide what we might consider a community benefit. Given that these academic institutions, whether private or public, are supported by public tax dollars that there is a responsibility then that that transfers. That the academic institutions need to provide, whether its through curriculum or whether its through workforce recruitment, the services back that reflect back to the community. The idea is very similar to the conversion of public hospitals. So that's kinda where that idea goes to. And, very quickly, to talk about supporting research through academic and nonacademic institutions, first is to support demonstrations that explore the use of community-based services. And, one of the things in particular is to look at how funding decisions are made, whether its at the grant review process or not. Especially looking at community-based research, who's on our review committees, is there an adequate representation of the URMs on the review committee, do the reviewers have adequate knowledge of community-based participatory research or an understanding of what it means to work with communities, and examining or creating different levels of funding or different funding criteria, so that its not only the academic institutions that can receive these funds, but also the community-based organizations who are very interested in also being part of the research process, but may not be able to adhere, currently, to the strict standards that we set in Federal funding levels, particularly through, you know, general, traditional funding mechanisms, whether they're R01s, P-50s or etcetera, etcetera. So, thank you. [Applause]

CHAIRPERSON STOKES: The next witness will be Mr. Franklin Zavala-Velez. But following him, I'll let other people line up at the mic. It will be Suzette Benn and then Lisbeth Melendez.

FRANKLIN ZAVALA-VELEZ: Good morning. My name is Franklin Zavala-Velez. I'm a member of [inaudible] Federal Committee for the Summit also [inaudible] and Commissioner for Disability of Miami Dade County. There is one thing that I realize in my life as an advocate for people with disabilities, no access for quality health care, especially when we are talking about prevention of diseases. Materials are not available in the language for the deaf. For the blind, there is no braille

material to understand about hepatitis C or HIV/AIDS or any type of diseases. I have had experiences in hospitals that they're required to have sign language interpreters for persons who are deaf and they don't get there on time and medical treatment is awkward and the hospital will take 3,4, or 5 hours even if the person had a heart attack. They can't get the question and information about if they are allergic to any type of medicines, until they get a sign language interpreter at the hospital. However, I find agencies that provide health service do not provide sign language interpreters for the communities who are deaf and hard of hearing. There is a lack of cooperation, collaboration between CBO and the disabled community. They are not being taken care of. They are not being involved under statistics, planning. They are not in your data. They are not in your needs assessments. And let me tell you something, there are 56 million Americans who are disabled. In my county alone, 13 percent of the population are disabled, 180,000 are hearing impaired, and 150,000 are the disabilities.

As Chairman of the Center for Independent Living, I have tested 175 deaf individuals for HIV and AIDS and hepatitis C. And to my surprise and the clinics, 38 percent are positive with HIV, 19 percent hepatitis C, and they have no knowledge or understanding of what this is all about. We need cooperation. We need to be working together and communities need to realize that they have people of disabilities in their communities that they have to serve. If you don't work together, you're not going to accomplish your goal at all. You are not going to succeed, what so ever, to take care of people with disabilities. People who are blind, people who have head injuries, people who have spinal cord injury, you have to realize that if you continue neglecting and put away people with disabilities, you are not going to do anything the right way. So, I'm asking you to work together with the Center for Independent Living throughout the States, which was established by Congress in 1975, and to also to work in partnership with CBOs. And, I'm asking CBO organizations, members of different and other States to please contact Center of Independent Living, the Deaf School, the Light House. Work with them. Together we will be able to accomplish the goal of eliminating disparities. Thank you very much.

SUZETTE BEN: Mr. Chairman, Committee members, good morning and I thank you for the opportunity to be able to address you. I come before you as a former Special Assistant for Health Affairs for Governor Wycher and also the First Commissioner for the Office for Health Care Access. Some of us do remember at one point in the mid-nineties. We were talking about universal access to health care. I would like to respectfully propose to you that you get that back on the agenda with one added word, universal access to state-of-the-art health care. [Applause]

The reason I add that is, thank you, the reason I add state of the art is because we are familiar with the data that

comes from the heart association, our own State data that speaks to the fact that God forbid, if I should show up at the hospital that I'm a board member of, in cardiac arrest, I will be denied the beta blocker or the aspirin, which costs a penny, because of what I look like. And, I think, as far as I'm concerned, that's no different to those Arthur Anderson and friends who swindle my pension funds, and they should be treated and viewed as in the same category, because that is, if we don't have our health than we don't have anything.

The one other thing that I would like for you to consider is, is that health care is a business. But, this is the only business where we are not looking at the bottom line. We have 43 million Americans still uninsured. We also spend upwards of a trillion dollars, but yet, we're not up there in terms of infant mortality or life expectancy for Americans. But we're not asking: Where are the dollars going? We're not saying that most of it is spent in the last month of life, none, very little on prevention as we heard. I think the other part with cultural competence. My son just graduated from Kellogg School of Management in International Marketing. Cultural competency is critical in that education because of it affects the bottom line. We need to address the bottom line. Thank you. [Applause]

CHAIRPERSON STOKES: The person at the mic was Ms. Suzette Benn. Ms. Ben you didn't give us your name, but I know that I had asked that you line up to be next to the mic. So the Committee just wanted to know who you were. OK. Thank you very much. Ms. Melendez?

LISBETH MELENDEZ: Yes. My name is Lisbeth Melendez. And in case you haven't noticed I am Latino. I am a lesbian. And, I'm here because, I stand in front of you ignored by this conference. Not just as a lesbian, but as a woman. My health care needs are nowhere in the agenda of this panel or this conference. Issues of domestic violence that affect lesbian, gay, bisexual, and transgender communities are nowhere in this conference. And, as my colleague and Executive Director Martin Ornelas-Quintero mentioned before, we understand and know that this is not a coincidence. It is a shame that in this day and age, in this country, we would ignore a population who sits in front of me, because I know some of you sit in front of me, and will stand by lesbian, gay, bisexual, and transgender populations not being addressed by a conference that purposes to address health disparities. Furthermore, I have a challenge for you. There is one thing you fail to do. There are many individuals outside of the doors of this hotel who would love to be here, who cannot afford 150 dollars to attend. It is an expensive conference. For racial and ethnic populations, not all of us have the monies to come attend something like this. And, it is a shame that you do not have enough scholarships or help to attend something so important for us. [Applause]

And last, if you can't do it, then you need to give us

the resources to do it. We need translation in the languages of the people who need to be in this room. And, if you can't address translation in these conferences, translations in Spanish, in API languages, in African languages, in any language necessary for us to understand what goes on inside these walls, you are failing. And, if you can't do it, trust us. There's a lot of us who can. Give us the money, we'll be here. We'll do it, but we'll make sure that they understand. So thank you for your attention. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Melendez. We're gonna ask witnesses Maria Scruggs-Weston and Ms. Drake from Boston to line up behind the next witness who will be Kinike Bermudez. Please state your name and affiliation. We'd appreciate it.

KINIKE BERMUDEZ: Hi. My name is Kinike, not kinky, although I've been called that many times. [Laughter, applause] That is Hawaiian. My name is Kinike. I'm a person who lives with arthritis, diabetes, and bipolar disorder. Let me say that again. I am a person who lives with arthritis, diabetes, and bipolar disorder. I was born in Brooklyn, New York. Until I was 6, I thought I was Puerto Rican. [Laughter] Everybody else was either white or black or Puerto Rican. Why would I not know that I'm Filipino-Hawaiian-Chinese? The world has changed. The minorities are no longer minority. And yet, we're treated as though we're minority. My body and my brain cannot be separated. The bipolar illness, as I stand and hear about physical and public health is treatable. I can function as an individual with treatment and support. And as a result of I'd say adequate care, but certainly not the best care, being second generation American I was very fortunate. But, then my mom came from the Philippines, was very good in making us assimilate. And, in that process of assimilation, I lost my culture, lost the language. I can say *Amagundan umaga.* I can say *Aloha, y'all.* [Laughter] And, I can say a little bit of a lot of things, because I was also military dependent.

I come before the advisory committee, because, who is this system for, if not all the people? How is the system going to affect all of us, if we don't do changes. I wear another hat.

I'm a consumer advocate for the National Asian American Pacific Islander Mental Health Association. [Applause] Thank you. And, I'm also a consumer advocate who is trying to educate and empower other consumers to not only vote, but to get involved in legislation that affects budget, that affects services that affect my life and their life. The platinum, the golden rule has been, do unto others as you would have them do unto you. I would ask that people look at the platinum rule. And that is to do unto others as they would like have done. Culturally competent, linguistically appropriate, culturally sensitive, ask and respect. The differences that make a difference in the physical, mental health care and recovery, and I strongly recommend mental

health parity now. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Bermudez. State your name for us.

MARIA SCRUGGS-WESTON: Good morning. My name is Maria Scruggs-Weston and for some reason, this is the second time I've been in Washington within a couple of weeks, couple of months, and all the mics are for vertically challenged people. I'm not sure why that is. We come tall and rude from Florida. [Laughter]

My name is Maria Scruggs-Weston. I'm the Project Director for the Sisters for Breast Health Program, St. Anthony's Health Care and also the President and Cofounder of Source of Health, Incorporated, which is a nonprofit organization created for the purpose of eliminating health disparities that exist within South or in Penalus County and in the county as well.

One of the things I'd like to do is compliment the Committee on comments that you've raised in relation to the National Center for Minority Health Disparities Strategic Plan Research. Dr. Stokes, I'm at somewhat of a disadvantage, because I have not had the opportunity to thoroughly review your letter.

But certainly, there are some points that I am hoping that the Committee would not only provide the NIH in writing, but also solicit input from community groups such as Source of Health, Incorporated, to support some of the very comments that you've made in your letter to Dr. Ruffin. And, the one that I'd like to make specific reference to, is the fact that the reference to Ain order for the research plan to be effective, that there should be more focus on developing and working with communities in all phases of research and training.@ And for some reason I find that that piece is very difficult for the health community. And maybe some of the other major focus areas. But, when we look at working with communities, traditionally what happens is the key to the work is funding. I've heard several comments relating to funding being directed to community-based organizations, and I see that finger going up already, so what I would like to do is to submit my comments to the Committee in writing and honing in on some specific recommendations on how NIH can actually engage communities more effectively in making an impact on health disparities. [Applause]

CHAIRPERSON STOKES: Thank you Ms. Scruggs-Weston. We'd be glad to receive that information from you. And we appreciate your reference to the letter. Thank you. OK. Straight from Boston? First witness we've lost this morning. Alright. Mr. Nick Calzoncit?

NICK CALZONCIT: Good morning. Thank you for the opportunity. The first thing that I would share with you is something that you already know to a point. And, that is that amongst minorities for sure, diabetes is disproportionate. We suffer from it a lot more. We also suffer from the evil tobacco industry that is advertising greatly in minorities. Hispanics, African Americans, females during pregnancy have high rates of

diabetes and if they smoke, there is sugar in tobacco, and that is the point that I want to make. Not everybody knows that, you might know that, but not everybody knows that. And, I refer you to a book called Sugar Blues. Duffy is the author, and it has a chapter on tobacco containing sugar.

Secondly, we just lost Dr. Satcher the Surgeon General. The greatest surgeon general that has ever served. Certainly in the areas of minorities and females, you are familiar with the works that he did. He left. I don't think that he left willingly, but he left. We have a new Surgeon General, getting ready to be appointed. Some very serious questions have come up about him. And I think you have the responsibility, although its going to be sensitive, to find out: What about those allegations? What about the reports? Is he suited to be surgeon general? [Applause] That didn't count for my time please. [Laughter]

All the comments about deafness, I'm a graduate of Galludet, and they are all accurate. One thing that I'd add to that is that Galludet, some of you know about it, is a world famous university, it's full of resources. The information that the gentleman before was talking about, that's all available. It's almost incumbent. You have the responsibility to contact the President Ken Jordan. If you haven't done it, you should have done it already. But, if you haven't done it, I think that would be a necessity. And, I'm sure the same thing is true in blindness and the other illnesses. And quickly, the tobacco industry is killing minorities much faster than ever. It's horrible they're breaking the laws. They're doing everything wrong. You have to have a whole section just on the evils and the corruptions and put those people in jail. They break the law. And, finally, Chicanos, Latinos, Hispanos, and I applaud the African American, I work very closely with all nationalities. I applaud the African Americans for being so strong and being here. But, I think, that just by observation, there may be a need for you to find better ways to bring more Latinos into this kind of a meeting. Thank you. [Applause]

CHAIRPERSON STOKES: For the record, just give us your name and affiliation, please.

NICK CALZONCIT: My name is Nick. The last name is Calzoncit. And, what was the other thing?

CHAIRPERSON STOKES: Your affiliation?

NICK CALZONCIT: Oh. I work with a lot of groups. The National Latino Council on Tobacco Prevention, National Alliance for Hispanic Health, World Health Organization. I guess, put down the Barrio Comprehensive Family Health Care Center, that's the one where I am mainly.

CHAIRPERSON STOKES: O.K. Thank you very much.

NICK CALZONCIT: Thank you sir. [Applause]

CHAIRPERSON STOKES: Ronald Sy or See? To be followed by Stella Nash and Reverend Jesse Brown.

RONALD SY: Thank you for the opportunity for hearing us

all in this panel.

CHAIRPERSON STOKES: Your name and affiliation please?

RONALD SY: I was about to start. My name is Ronald Sy.

I work for AIDS Services in Asian Communities in Philadelphia. My comments will be around the need for translation and interpretation services. Currently our agency is dedicated to providing culturally sensitive and language appropriate HIV-related services to Asian Pacific Islanders. But, because of the need for translation and interpretation, we decided to collaborate with other organizations, Latino organizations, API organizations. And currently we're exploring partnerships with other health organizations to provide translation/interpretation services around HIV services, which would include testing and counseling, and this is through doctors and social services.

Now my comments really stem from the fact that, according to Census, 87 percent of API immigrants or other immigrants, claim to be first generation. About 65 percent speak a primary language other than English. What disturbs me is, according to Office of Civil Rights, we do have the right to have access to translation/interpretation services. But, there are no standards to back that up. For example, a hospital can claim to have a Chinese-speaking worker. But, this Chinese-speaking worker will be either the janitor on the third floor that works from 12 midnight to 6 a.m., or a sixth-generation Cambodian man who can't speak the language. We've heard several horror stories.

Like, a client was told that he had to take his medication three times a day. The person who was interpreting for him was a candy stripper misinterpreted and told him "You have to take three pills three times a day." So, you can just imagine how horrifying that is.

And until recently, there was an infamous study done in Chicago called the GOMER Study. It's actually an acronym for Get Out of My Emergency Room, because we cannot speak your language.

And this is not set out to be loud, because you think that speaking louder in English would make you understand them. [Laughter] And I really have issues about what are the standards or cultural competency. You are not culturally competent, if you order Chinese food every day, or you have a map of Asia. That does not make you culturally competent. OR, if you have a worker who looks Asian who doesn't speak the language, I'm sorry, that does not help. [Applause] We always talk about health care should be for all people, but we do not take care of the least of our people. One last, a couple of things that, you know, I always share in meetings like this, you know, when you call me, I don't necessarily speak Asian. Now, I don't know what that means, because I speak Filipino. And, one more thing, we are not Oriental, because we are not furniture. Sorry. [Applause]

STELLA NASH: Good morning, and thank you for the opportunity of being here. First of all, when I looked at this conference, I thought about health. And you said health, and

it's a complete state of physical, mental, social, and emotional well-being. But then when I looked at it I thought, in a sense, in the agenda, I did not see anything on there about food, nutrition, and its relationship to health and well-being.

[Applause]

CHAIRPERSON STOKES: Can I interrupt you for just a moment? Would you please identify yourself first.

STELLA NASH: Yes sir. My name is Stella Nash. I am a registered dietician. I am Regional Nutrition Director for the United States Department of Agriculture, the Mountain Plains Region, Denver, Colorado. I think we need to provide education in the area of preventative care. As I looked at the agenda, as I said, there was nothing that addressed nutrition and physical activity. And, many of our health problems are related to diet.

As you can see, there is obesity, hypertension, high blood pressure, and all of that. And, I think what we need to do, I know funding is very important, but we know that funding is limited. So what we need to do-- [tape ends]. Thank you very much for your time.

CHAIRPERSON STOKES: Before the next witness, let me just make a statement. Several witnesses this morning have made suggestions or comments relative to the manner in which this conference has been organized and made references to certain subjects that were or were not made a part of the conference, etcetera. I think it's important for you to understand that this conference was not organized by this Advisory Committee.

[Laughter] This conference was organized by the Office of Minority Health of the Department of Health and Human Services. Now, the head of the Office of Minority Health, Dr. Stinson, does sit with our Advisory Committee. But, the Advisory Committee had nothing to do at all, in terms of arranging the Summit conference, which you are currently attending. We do appreciate the comments you've made. And, to the extent that we have the responsibility, we will certainly convey to the Secretary of Health and Human Services the kinds of concerns that have been expressed this morning. But, I think it is important for you to understand, we did not organize this conference. [Laughter and applause]

Your name sir?

JESSE BROWN: Reverend Jesse Brown, Executive Director of the National Association of African Americans for Positive Imagery, better known as NAPPPI, and also the [laughter]

CHAIRPERSON STOKES: Now we've got Kinky and Nappy. [Laughter and applause]

JESSE BROWN: And as they would say, AIt's all good!@ [Laughter] I'm also President of the World No Tobacco Day Coalition here in the United States as well. I come to, and I'm glad HHS has allowed you guys to come into the house and hold this hearing. So, we'll give proper due where its due here. I want to bring, as the agendas have been put forth on the table,

there is one, another, critical agenda. It's not any more important or less important than the ones that have already been provided, but equally must be taken into consideration. As we develop programs, one of the things that we need to do is to figure out better ways to maximize what little bit we do have, with little monies we do get, with little research we do get to do, and what little programs we get to put out there. And, probably one of the big components missing in many of our programs is the marketing of these programs in our various ways.

It's nice to have Madison Avenue, let's just see if we can have them do something in Madison, Wisconsin, too, with some of these programs we currently have.

The promotion and advertising of these programs must be a critical component to everything that we do. It's nice to have a good immunization campaign, but if nobody shows up to get the shots, what good is it? It's nice to have breast cancer treatment programs, but if nobody comes to get the screening, what good is it? This is critical and I hope that maybe you can influence both the flows of dollars (toward marketing) and some of us who create these programs and write these programs and promote these programs to actually write them into our grants. And, let's help also to educate grant funders to the point that marketing is an important part of getting the grant. Not merely coming up with the program and having it there to sit on the shelf. [Applause] And I just want to add one piece to that. Yes, like everyone else before me has said, the programs must be culturally competent, must be relevant, must be designed by the community, carried out by the community, so that the community feels the honor and in fact succeeds in raising the level of health in our own communities. If we want healthy families and healthy communities, we can do it. [Applause]

SUKI TERADA PORTS: I would just like to give a point of information. And, I am sorry to interrupt, but I think that people have misunderstood that this body here listening to our testimony is indeed not responsible for the conference. There was a planning committee, we were also not given the privilege of having the final word for the conference. And, I think you ought to understand that the conference was originally scheduled for September of 2001. But at the request of Secretary Tommy Thompson, so that he could have more input, he requested that the conference be put off. He is now in Barcelona for this week. And I think you need to understand that this was a definite slap in the face to the Office of Minority Health, which worked very hard under the directorship of Dr. Stinson. And, I think it was a definite slap in the face of the communities of color. And, I think you should not put the responsibility for the changes in the agenda, because those were all okayed by the Office of Secretary Thompson who is now in Barcelona. [Applause]

CHAIRPERSON STOKES: Thank you. I think this might be a good time for us to take a little break. For those witnesses,

the people who would like to testify before the Committee who have not yet registered, please register at the table outside so that your name will be given to me. We'll come back in about 10 minutes.

P-U-B-L-I-C H-E-A-R-I-N-G R-E-S-U-M-E-S

CHAIRPERSON STOKES: For the record, let me repeat again: All persons who want to testify before the Committee are requested to sign up at the desk immediately outside the door. Our intention now is to proceed for 1 hour until 11:45, at which time we will conclude testimony before the Committee. And then the Committee itself will have a 15-minute wrap-up period. Once again, we are going to hold each witness to 3 minutes testimony.

We'll give you at the end of two minutes, we'll give you notice that you have 1 minute left. We'll ask you to conclude at that time. With the cooperation of everyone, we'll be able to get a large number of people who want to testify, and give them the opportunity to do so before we have to conclude at 11:45. We'd like to hear from everyone. We think that it is important to hear from you. And, with your cooperation, we'll be able to do so.

Let us at this time then, begin with, I'm having a little trouble with some of the writing, so, it's not my reading, it's your writing. It looks like Gem P. Daus? O.K. And then, he'll be followed by Charlotte Kennedy, Nicole Laing, Lucille Johnson, Marie Sanchez. We'll ask each of you to please give us your name and your affiliation, and we look forward to hearing from you at this time.

GEM DAUS: I thank you Dr. Stokes. You pronounced my name correctly despite my bad handwriting. I take responsibility for that. My name is Gem Daus and I work for the Asian and Pacific Islander American Health Forum. We're a national organization located both in San Francisco and here in Washington, D.C. And, I wanted to give you comment today on specifically the definition of under-represented minority. The Association of American Medical Colleges recently considered changing their definition of under-represented minority or URM. And, they asked for comment. And, the Health Forum did submit comment, which I will give you copies of later. I also wanted to let you know what the essence of what kinds of changes we asked for. Especially since they haven't changed their definition since 1970. As you all know, the country has changed dramatically since 1970.

First I should commend the Bureau of Primary Health Care for their definition of URM, because it's actually, it goes further than AAMC's and just to read it to you, it says: "Under-represented minority" for the purpose of the Centers for Excellence Program is defined as black or African American, American Indian or Alaska Native, Native Hawaiian or other Pacific Islander, Hispanic or Latino, and any Asian other than Chinese, Filipino, Japanese, Korean, Asian, or Thai. Now what

is notable about this definition is the disaggregation of Asian ethnicities. One of the things that we always advocate for that level of disaggregation, because if you look at the Healthy People 2010 objective, it only shows the aggregate Asian number, which misleads us to think that in fact there are enough Asians in the health fields. So, what we want you to consider is, of course, the heterogeneity of the Asian Pacific Islander populations, that there are many different Asian ethnicities, languages, cultures that need to be represented in the health professions.

The Census 2000 data on professions broken down by race and ethnicity will be available by the end of the year. So that will be a great opportunity to look at the number of people in the health professions. And, look again by specific ethnicity who is actually represented in the health professions. The other thing to make sure to disaggregate though, is to look at the distribution by speciality area and also by geographic area, so that we are not looking at just one indicator, but actually a lot of indicators that will really put the providers that we need in the communities that they need to be in. Thanks. [Applause]

CHAIRPERSON STOKES: Thank you very much Mr. Daus. Just give us your name and affiliation.

CHARLOTTE KENNEDY: I'm Charlotte Kennedy, Director of Intercultural Medicine for the University of Tennessee College of Medicine and Clinic Psychologist in the Department of Psychiatry.

Mr. Chairman and members of the Committee thank you for the opportunity to comment this morning. By way of further introduction, Memphis is in the Delta Region, a wide area that includes counties in Tennessee, Arkansas, and Mississippi (near the Mississippi River). It's one of the poorest regions in the United States. Health statistics rank the Delta counties in the bottom 10 of all U.S. counties for worst life expectancies. African Americans in Tennessee have higher than national averages for rates of heart disease, cancer, stroke, and infant mortality. Compared to African Americans nationally, African Americans in Tennessee experience higher rates of death from heart disease, hypertension, Alzheimers, cerebral/vascular diseases, arteriosclerosis, homicide and nutritional deficiencies. We also experience significantly higher rates of death than white Tennesseans from heart disease, cancer, stroke, infant mortality, HIV, prostate cancer, and it goes on and on.

Memphis has approximately 55 percent African Americans in the city, 47 percent in the county. We have a growing Hispanic population, and Memphis is one of the major resettlement sites for Southeast Asian refugees. The statistics that I mentioned earlier in terms of health disparities exist in spite of the fact, particularly evident in Memphis, that the University of Tennessee Medical School is in Memphis. And, Memphis has major hospitals providing health care, one of the largest hospitals in the nation. I would encourage this Committee to

focus on funding and support for human resources to increase funding to medical schools that train physicians and future health care workers. I would further recommend that this funding and support be directed toward training future health care workers on the sociocultural influences on health care, so as to increase the human resources that exist for providing culturally competent health care. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you very much Dr. Kennedy.

NICOLE LAING: Greetings. My name is Nicole Laing. I am a registered nurse. I work for the Inpatient Services for Child Psychiatry, Yale New Haven Hospital. I not only come to you as a nurse, but as a student. I am an example of one of the individuals from another country other than the United States. I reside here, I've been here for 11 years and I want to be part of the solution in eliminating health disparities. I have been blessed enough to have a solid educational background in Jamaica.

I came here after I graduated high school. I have many degrees thus far, and I am in a child psychiatry nurse practitioner program at the School of Nursing at Yale New Haven.

I am concerned that there are not adequate opportunities for students who are not citizens of the United States to get financial support to progress in their education. I am in a master's program. I would like to get a doctorate. To this point I have supported my education through scholarship money and a lot a lot of loans. [Laughter] Now that I am at Yale, I am feeling the pressure because I have 2 more years. I have been getting support through the School of Nursing through nursing scholarships and more, more loans. I'm aware that the Department of Health and Human Services has money available and you're so supportive of nursing students, yet, the first requirement is you have to be a U.S. citizen. That totally scratches me out of the box. I would like to continue my education, maybe be a part of the Advisory Committee some day. But, I feel like my only opportunity, or my only way of getting that accomplished is to get a U.S. citizenship. If you don't help us, we will become one of the disparities in health. There are a lot of us out there. The majority of the students in my class at Howard University, before I graduated, were from other countries, Africa, the Caribbean, and a lot of them were not citizens of the U.S., and we need the financial support. Because a lot of the people that we're gonna be dealing with as professionals are not only U.S. citizens, and we need to be culturally competent. So I implore you to find funds available for us, so that we can get our education, because there are a lot of us out there and we want to help. And I want to be a part of the solution in eliminating health disparities. So help. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you Ms. Laing.

LUCILLE JOHNSON: Good morning. My name is Lucille

Johnson. I am the Associate Director for Health Initiatives at the Metro Denver Black Church Initiative. The Metro Denver Black Church Initiative is a church association for community service and we represent nearly one-third of the black churches in the Denver metro area. We believe that partnership and collaboration are key when addressing health disparities. And we believe that we can do together what none of us can do alone. We partnered with organizations such as the USDA, University of Colorado Health Sciences Center, Denver Health, the Colorado Health Department, GLAXO Smith-Klein, Pfitzer, American Diabetes Association, Komen Breast Cancer Foundation, and many more organizations. Together we are standing in the gap to educate our folks around health, education, and outreach, because there are other major State initiatives going on, but they don't address the needs of the African American community. Our motto is similar to that of the Civil Rights Movement in that we see the value in disseminating information through the churches and mobilizing for positive social change through the churches. It's modeled its work so if it's not broke, we're not gonna try to fix it.

My challenge to you would be to open to faith-based initiatives and to shift your paradigm in thinking in terms of what that may mean. While we do provide technical support to some of our churches, well to all of our churches that want it, I would challenge you not to make the process so cumbersome that the organizations lose sight of who they are for the sake of the Almighty dollar. Keep in mind that the primary focus of the church is the Gospel of Redemption. And, I just wanted to say, that if you'd like to take a short, brief, 8 and a half-minute look at a strategy that is working well, I have a video here for you to view. And, it's about obesity prevention. We've mobilized with the Center for Human Nutrition and the University of Colorado Health Sciences Center together to get step counters on people and look at workable, fun strategies to increase physical activity and reduce obesity. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you Ms. Johnson. Thank you also for the copy of the video.

MARIE SANCHEZ: Good morning. Thank you for the opportunity to be here and make comments today. I am Marie Sanchez. I am the Executive Director of the National Latino Behavioral Health Association. As a national organization focusing on Latino behavioral health issues, I have a lot of comments. But, I will narrow them down. One of the recommendations addresses one of the areas that is listed today: increasing diversity of the health professions. As many of you know, our rural areas suffer greatly from lack of diversity of health and mental health service provision. That is a major concern of NLBHA. Second, access to education is very challenging to people in rural areas, which include a lot of ethnic minorities, and that's another concern of NLBHA's. So what

I would like to go to as a recommendation is that we look to how we train and professionally grow our own service providers.

Often the best recruitment strategy is to home grow staff who by identifying and supporting staff already employed by the agency are committed to living in the community where services are provided. Such persons are often not traditional students, but they may lack completed degrees or may not have attended college in many years. But, with financial support, encouragement, and accessible educational opportunities, they may become the most loyal, productive, and involved with the service community in their areas. We need to look at funding the development of community-based training programs, bringing educational opportunities closer to home, perhaps by combining university training and mental health community service delivery to increase the number of bilingual/bicultural service professional staff. We also need to develop programs that are oriented to the student and not to the institution. Programs should be built around the lives of students who are interested in receiving an education, but are not able to leave the community or move far away to campus to access a program. Perhaps that means building culturally competent educational programs. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you Ms. Sanchez. The next persons will be Alice Richie, followed by Fanny Hicks, and Walter Harper.

ALICE RITCHIE: I want to thank the Committee for letting me speak. I'm Alice Ritchie and I'm from Northport, Long Island. I work for the Veterans Administration there. I'm a registered nurse. My focus is on decreasing cardiac risk factors in women. O.K. On Long Island there's over 10,000 women veterans. In Northport they have opened this year a women's health program, so I would like these women to access the program.

There is a survey available that's been designed by three nurses and two doctors that could be distributed to all these women veterans. It would assess and talk about different demographic material and also their cardiac/vascular needs. Depending on the response and their population clusters in the community, different programs could be set up in approximation to where these population clusters are. In return for perhaps having the educational program in the community, because it should be in the community near where they live, it could be set up in local churches. And the response for that, in exchange for the space, women from that catchment area that aren't veterans should be eligible also for the educational program. Two things are accomplished in this way, particularly if the program is singled out for minority women veterans and minority women in the community. It doesn't have to be singled out there. It could be larger groups, but minority women are of an increased risk as far as cardiovascular disease and we are talking here about

eliminating disparities and racial problems. This way two things will happen. We have in the veteran community many, many minority people that come in and use this as a way of life. They will have access as preventative services in the future. The other part about having in the community, an ongoing educational program is that the persons, particularly minorities will have access to all this education. Not only that, but they have made contact with the woman veteran. And we all know that there is a great sisterhood among minority persons, that's really culturally part of their, I would say, their essence. And so I would say that would be a good example of cultural competency demonstrated. Thank you again. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Ritchie.

FANNIE HICKS: Good morning. My name is Fannie Hicks. I'm from Midway, Alabama. And I bring greetings [inaudible]. I'd like to address mental illness. I'm a consumer. I'm affiliated with the Alabama Minority Consumer Council. It's hard for me to get help, especially for minorities in the State of Alabama. I've heard other people saying the same thing. If you are a minority, it's hard to get help. What I'm trying to do, trying to get minorities from taking their mental problems as a scapegoat. They start drinking, doing drugs. You confront them, they say: **A**Hey, I'm a nobody. Nobody is gonna hire this crazy person. Nobody wants this person working for them. And, they've got this negative attitude about themselves. And, I'm working on trying to get them to realize they are somebody. I have two degrees. I used to teach school. Now, I'm a field specialist for the State of Alabama. For 7 years nobody would give me a job. I'd say: **A**Please give me a job digging ditches. They thought I was joking, but I was serious. [Laughter] But no one would hire me. So one of the problems, we need more access to grant money, because I got this goal. Minorities need help, especially those with mental problems. They need to feel good about themselves. We are going to have to have some money to do outreach programs to these people. We have a lot of them that commit suicide, are homeless, all of that. I think, if you all were to go to address these things, then you can help other minority consumers with mental illness to be productive in society. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Hicks.

WALTER HARPER: Good morning. My name is Walter Harper and I'm the coordinator of the Minority Health and Wellness Program for the Urban League of Rhode Island, one of the affiliate groups of the National Urban League. Secondly, I am currently completing my doctoral dissertation studies at Brown University in Providence, Rhode Island. I come to you today, and hopefully I'd like to beg the forgiveness of the Committee and the group here if it has already been mentioned. But, I just wanted to make sure that this issue has been raised this morning, for this session, and that has to do with the relationship

between the fast food industry and school lunches. [Applause]

It is very difficult for me as a public health professional to promote health and wellness programs, especially in elementary and secondary schools in Providence as well as in targeted communities in Rhode Island, when in the lunchrooms, what I'm teaching is not being reflected. So that is basically all I wanted to share. Thank you very much. [Applause]

CHAIRPERSON STOKES: Thank you very much Mr. Harper. Then next persons will be Erica Harriott, Jennifer Kunkel, and Jesse Soriano.

ERICA HARRIOTT: Hi. Thanks for having me up here. My name is Erica Harriott. I'm with the National Hospice and Palliative Care Organization. One of the areas that I wanted to touch on, which I just didn't see was being addressed as part of this panel was end-of-life care for minorities. We look at health care and then we forget that in the end all of us are going to die at one point or another and it's always something that is planned last. I have a special interest in minority health care because I am the only manager that works for the organization that is a minority. And, with that, I am also an international person of West Indian descent and I look at my family and for the first time we had to use hospice care for my grandmother who died at age 102. And her mother before that lived to be a hundred. So I figure I have a longevity here, so I am going to use it while I can. [Laughter]

One of the areas that I'm asking for basically is access to research to improving health care for minorities across the board, not just for African Americans, not just Asians, or Latinos. Last year, only 8 percent of African Americans used hospice care and it's not caused by basic lack of knowledge. It's caused by psychosocial issues that's been brought up in health care and other issues that can be overcome with research and education. I'm also asking for studies to be done that will show that health care cost can be reduced through effective health care planning. Studies that we've done through the Lewin Group and the MacMillian study shows that by planning effectively, not waiting until the last days of life, you can, in essence, reduce your health care dollars by using effective health care planning.

Part of that is using hospice care and appropriate health care when necessary. That can be done also through community-based and also through national research. And that's basically what I'm asking for, increased funding and increased education and increased access on the part of all providers and consumers of health care to include end-of-life care as part of your planning. Thanks. [Applause]

CHAIRPERSON STOKES: Thank you Ms. Harriott.

JENNIFER KUNKEL: I'm Jennifer Kunkel. I'm with the AIDS Planning Coalition of South Central Pennsylvania. I'm going to speak as a minority researcher, because I'm the coordinator of research for a 14-county region of Pennsylvania. I and several

other API professional organizations are collaborating in the City of Philadelphia to do an API study regarding two questions.

The basic questions are: What is the knowledge base of APIs with their risk of contracting HIV and what do they perceive as barriers for testing for HIV? This started about 2 years ago. I contacted several Federal bodies including the CDC, HRSA, and also the National Minority AIDS Council. What I got through my initial process was a lot of hurdles. I was told that the study didn't fit this. I was told the study didn't fit that. I was told the funding was available through this avenue or that avenue. It became a 2-year nightmare. So, I approached the State of Pennsylvania. Instead we got very creative. And, it was interesting, because when I first approached the State, what they said to me was: "Well, Jen, there's not a lot of data out there on APIs, so therefore, we don't know if we can fund this." I'm thinking to myself, did I just lose my mind? And, I thought to myself, alright, let's do some basic education here. So, I did a written proposal, showed them what the lack of data suggested in accordance with what the world statistics are and also the immigration pattern, and they got their clue. And they said O.K. let's get creative and fund this. And that was fine.

My comment to everyone right now, for HHS, is folks what I need desperately as a minority researcher is for HHS to get its Federal-level entities together and figure out ways to help support minority researchers such as myself. [Applause] Don't just tell me what you can do, ask me instead what I can do. [Applause]

CHAIRPERSON STOKES: Thank you Ms. Kunkel. The next person is Mr. Soriano.

JESSE SORIANO: My name is Jesse Soriano. I'm the Director of Ethnic Minority Affairs for the Health Sciences Center at the University of Utah. I'm also a member of the Utah Governor's State Council on Health and I'm also the Chairman of the State Ethnic Health Advisory Committee. My purpose for being here is fairly simple. I'll make it very quick. First of all I want to let all of you know that we have minorities in Utah. [Laughter] The response points out what a lot of us in Utah feel.

Approximately 12 percent or more of our population in Utah is Hispanic/Latino. That's been a dramatic increase since the last Census. Approximately 16 percent of our population is minority.

I think, if I'm correct, I haven't looked at the latest Utah Medical Association books, but we probably have two American Indian physicians in the State. And I could probably count the African American physicians on one hand, in Utah, and a handful of Hispanic/Latino physicians.

There is a tremendous need for health care professionals in Utah. That brings me to my second purpose and that is to invite all of you to move to Utah, please. [Laughter]

Not all Utahans are going to express the same desire, I do

however. It's a beautiful State. It's an exciting State. I think it's a growing State. And, I think you'd be surprised, if you've never been there, you'd be surprised. I moved to Utah from this part of the world, from Fairfax. And, while it was quite an experience, it's still a beautiful State. Finally, I think I'd like to invite the Committee here to hold one of your meetings in Salt Lake City. That is a place that I think would certainly profit by your being there, by your presence there. We don't get too many outside minority professionals coming in and talking with us in the State of Utah. I would invite you all and again there is a greater need for health care for minorities in the State of Utah as there is anywhere else. The numbers might be a little smaller, but we're also more isolated. Don't overlook us. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you Mr. Soriano. If Dr. Stinson will pay for it, we'll come. I understand Ms. Bobbie Drake is now here. I called her earlier. Bobbie Drake-Saucer? And, she will be followed by Niem Nay-Kret, I believe, and Ujima Moore.

BOBBIE DRAKE-SAUCER: Good morning. I'm sorry, if you called me earlier and I wasn't here. But I'd just like to address the panel this morning and share with you my concerns. I'm concerned about a very serious problem among black women, black women's health issues. I'm a lupus survivor. I don't call myself a sufferer, because I've survived since 1987. It took over a year to be diagnosed with this disease. And, my life has been life altering since then. So I am a survivor as far as I'm concerned.

I'm concerned about the high prevalence among black women. Four out of every 250 black women have lupus as opposed to 1 out of every thousand white women. I think that is a problem. Seventy percent of all lupus-related deaths are black women. CDC just took a look at that, just came out with some statistics. I know you all through the Office of Women's Health have just put out, made some monies available. Unfortunately, they are primarily through the primary health care organizations for each State or the Lupus Foundation or the Arthritis Foundation. Those are traditional organizations that do not have a clue what to do around black women and their issues related to surviving with lupus.

As a matter of fact, I have an organization that is 6 years old. It's called Women of Courage. It's for black women and their families in Boston. And, it's to figure out how to cope and survive and live. We have over 200 members and we're working real hard to keep our women alive every day. We have very little support, very little money. We would like to know, if we could, first of all get some help from somewhere. If somebody can take a look at the data. If we can have some registries. We don't even know how many black women in this country have lupus. You know what I'm saying? There are no

State registries, there are no local registries. I couldn't even get statistics to tell you in terms of how many women in Boston have lupus.

We recently got a study funded, an [inaudible] study to take a look at the high prevalence in Boston. We still don't have the numbers yet, because it was just doing a hospital-based study. So, we have a high prevalence, but we don't know how high it is. Because out of 17 hospitals, 27 health centers, and all the other private providers, we still don't know, because we don't have enough money to find out what is going on. So, I am asking you to really take a look at this problem. It's serious, because the disease is chronic. It's incurable and it's potentially fatal. Most often fatal for black women in terms of kidney failure, other chronic failures in terms of the systemic measure, they just don't survive. Most women don't survive any longer than 5 to 10 years. So I'm asking you to take a look at this very serious problem. I mean the medical community knows about this.

It's not a surprise, O.K.? Unfortunately, the women that are affected the most drastically are black women. So, please take a look at this. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you Ms. Drake-Saucer. Ms. Niem Nay-Kret? Ms. Ujima Moore?

UJIMA MOORE: Hi. My name is Ujima Moore. I'm the Coordinator of Intake and Women's Services for the AMASSI Center of Los Angeles. We provide free and low-cost mental health services, fitness and nutrition services. Part of the answer on the whole health disparities in minorities is sitting right here in this room. We're a community-based organization, and a lot of these agencies know that we are the answer. We are already culturally competent. We collaborate, we work together.

One of the largest problems for a lot of CBOs is funding a lot of people. We do network, we do work together out of necessity, and one of the things that has been kind of impacting the work we can be doing is fear. A lot of agencies who do provide the same type of services are afraid to collaborate, because, O.K., if I collaborate with you and you send more people my way, what about my funding? What about my numbers? If there is adequate money and funding for agencies like all of ours, then that kind of actually answers a lot of the questions here and impacts our communities in positive ways.

Right now in L.A. County, we're facing huge health budget cuts. And a lot of the agencies that were providing health care are closed, will be closing. Trauma centers, clinics, so they are relying now on our community-based organizations to pick up the slack. Our own Health Care Deputy Pat Miller said that ARight now, when 2003 hits, there are just people who won't receive health care period. It's not a case of do they have insurance, do they have Medicaid, or do they have Medicare. It doesn't matter, because they don't have anywhere to go. So our community agencies are the places they can go to.

But, if we're afraid to collaborate, because, I'm worried that my numbers will drop, because I don't have money. And, we're currently not worrying about that, but in the coming year, that's gonna be a problem that a lot of the CBOs are gonna be facing. So, there needs to be adequate funding for everybody so that we can collaborate, so that we can pick up the slack, because right now, L.A. County, people who are right now receiving substandard health care, won't be receiving health care at all. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Moore. Our final witnesses this morning will be Gerlinda Somerville, Vivian Wang, and April Taylor. Oh. I'm sorry, one more. Shahanaz, oops the writing is getting worse. [Laughter]

GERLINDER GALLEGOS SOMERVILLE: My name is Gerlinder Gallegos Somerville and I work in the area of HIV and AIDS prevention. I have two comments. First, I am speaking to you today as a Hispanic woman concerned for the health of her people, particularly the people who cross the U.S./Mexico border to work in the United States. I would like to remind the Committee that the health concerns along the border are the health concerns of the entire U.S. as well as the entire country of Mexico. For example, migrant farm workers are exposed to and expose others to many risks for HIV/AIDS as they travel as far north as the Canadian border and then return to their home villages in Mexico. Border health issues cannot be ignored. Resources for research, health care access, and prevention along the U.S./Mexico border will positively impact national health care in both the U.S. and Mexico.

My second comment is, recently there was a call for nominations to this Advisory Committee, and I'm wondering if you can tell us what the status of those nominations are and when we will know the results of those nominations. Thank you very much.

I appreciate the effort to address the committee. [Applause]

CHAIRPERSON STOKES: Dr. Stinson is going--

DR. STINSON: Let me respond to the question about the Advisory Committee. According to the charter on the Advisory Committee there are rotations on and off the board. You are correct, we solicited applications over the past several months.

There are some members of the current board whose term will be expiring at the end of this calendar year, at the end of December. Those applications will go through a review process internally within the Department and recommendations will be forwarded to the Secretary of Health and Human Services, and the Secretary makes appointments of who will be on the Advisory Committee. The announcement of the new members, we anticipate will probably occur sometime in December, prior to the expiration of some of the current members.

[Inaudible]

That has not been established, so there is no way for me to tell you who are all the people that will be involved in that review. That will be determined.

CHAIRPERSON STOKES: I think it was reported to us yesterday, an update given to us, that there are currently 85 applicants on that list. O.K. Next? Is April Taylor here?

APRIL TAYLOR: Good morning. I have to adjust this for my height a little bit. I'm coming to you from the good State of Massachusetts. I direct the Cancer Prevention Program and the Elder Health Program for the Boston Public Health Commission. I'm also coming to you from Boston with the energy that our commission just held a conference on the illumination of health disparities and race in the City of Boston, where it was a community effort and over 500 people attended at the JFK Center.

We had some stellar speakers and community people who were talking about the fundamental issues of race disparities. At that conference two important things came out. One was that in terms of the goals of Healthy People 2010, instead of looking at the percent-- [tape ends] reduction of health disparities. We should probably look at the overall rate of reduction of health disparities, which would make it much more equitable. The second and most fundamental thing that came out from the conference is that people thought that we should look at real causes, the systemic causes of why we have health disparities, and that was the issue of racism that plagues our society. So, I think for a conference that talks about the elimination of health disparities, we really need to put the issue of racism and social exclusion on the agenda. Thank you very much. [Applause]

CHAIRPERSON STOKES: You didn't give us your name.

APRIL TAYLOR: April Taylor. I'm sorry, and I have two comments that could help the committee on framing the discussion to talk about not only the theoretical contributions and academic contributions about the theories of racism, but how we can make some practical applications, if I can submit them.

[Inaudible]

CHAIRPERSON STOKES: Is Vivian Huang in the room. O.K. You are next.

VIVIAN HUANG: Hi. I'm Vivian Huang with the California Primary Care Association. We're a statewide organization representing community clinics and health centers across the State. As many of you know, community clinics and health centers serve medically underserved populations and really serve as a safety net for the uninsured and MediCal populations who may not be able to receive care elsewhere. One of the things that I was really excited to see on the agenda for the HHS Advisory Committee was the discussion about how to increase diversity in health professions.

Forty-four percent of community clinic patients in California are limited-English proficient, and over two-thirds represent communities of color. So, obviously, an important issue is how to recruit and retain a workforce that really looks like the population it is serving. One of the strategies that we've worked on in California is having community clinics be part

of a residency training program. One of the examples I wanted to highlight was Golden Valley Health Center that has actually implemented a training program for its residents that includes a clinic once a week on the specific topic of culture. So every week there are different lectures. There could be videos to talk about a specific culture. There's also a discussion about specific case studies of patients that have come through and some of the different cultural issues and barriers that come out. And, this serves as a tool to train residents so that they are able to better understand and appreciate other cultures and know how to serve that population better.

One of the recommendations I had on a national level is to really look at how the HHS Advisory Committee could really work with medical schools and other health professional training programs to reform their current education and curricula to include more training on how to be more culturally appropriate and also how to serve limited-English proficient populations. Even if the provider doesn't speak the language, they need to be trained on how to use an interpreter and what is the best way of insuring confidentiality and making sure that family and friends are not used as interpreters, but to use professionally qualified, competent interpreters.

The other comment I want to make was that because of the high cost of medical education incentives are also needed to try and recruit health professionals to underserved areas and so that should include not only looking at the National Health Service Corps, but also looking at how to make sure that the applicants through that program are culturally and linguistically appropriate, and trying to get doctors that do speak another language or have received significant training in that area. Thank you. [Applause]

CHAIRPERSON STOKES: Shahanaz?

SHAHANAZ ARJUMAND: First I'd like to thank you for providing this forum to voice our comments. My name is Shahanaz Arjumand. Throughout my career, I have found great satisfaction in helping the challenged such as the children's health issues in the State of Florida where you have a lot of elderly and Hasidic community, Hasidic women in New York as well as Japanese women's needs. And, today the needs of the uninsured immigrants and minorities as well as the Muslim community are what I am addressing for this forum.

Today, I stand before you representing a new community-based health services organization called ACHAMPS,® which stands for Community Health Alliance and Muslim Professional Services. We are a nonsectarian, referral organization providing health care services, educational programs, and liaisons to various health organizations in New York. We are currently being pulled to provide similar services in New Jersey and Connecticut. We primarily work with community members who are uninsured (which is about 43 million) and ineligible for Government programs or have

linguistic, cultural, socioeconomic, and faith-based failures to accessing health care services. Our strategies to improve health care diversity include, and are not limited to, presenting role models, demonstrating opportunities in the field, conducting community road show presentations, engaging children through essay competitions, and enlisting participants for various research studies, recruiting volunteers to experience many opportunities in health care, and offering internships.

This newly focused research on South Asian, African, and Middle Eastern communities, since there is very little information available on these groups, it is a big first step for this community to participate in such research. The two active studies we are conducting are breast cancer awareness and post-9/11 stress on focused, targeted communities. There are many cultural and environmental issues that are being demonstrated in the preliminary results. Many of them define health and health care services based on their cultural environments. As we struggle to define help and communicate the ever-changing health services offered in target States, we found that bureaucratic barriers to health care promote the use of ER as a primary care provider.

Our key challenges that we have limited health care professionals representing the diversity in the community to continue to provide community-level education programs. At this time we are being pulled to represent over 2 million people in the area with a handful of health care providers that represent the focus community. We also have about a million Muslims in the New York area. After 9/11 many of them were harassed by health care professionals. This is truly an embarrassment for our profession. We know there is a need to recruit talented students to pursue health careers, yet there are many cultural biases about various health professions such as nursing as a female only profession in some of these communities. To alleviate some of these biases we are planning to provide health care career counseling and require partnerships to achieve our mutual goals.

CHAMPS is a unique, faith-based community health organization that tries to provide consistent messages through our educational services. Many hospitals, health care organizations, State and City agencies are struggling to find community liaisons representing the diversity of their communities. We expect to partner with our health care matrix partners to achieve positive results. To be effective, we will need more than just volunteers. And, like every organization, we will require funding. At this time, Federal, State and city grants create great challenges for newly formed community-based organizations. Much was promised through the Faith-Based Initiatives and was not delivered. We firmly believe that organizations cannot only provide members for a racially diverse and ethnically rich community, but we can be extremely effective

in conducting research studies and helping to improve health care outcomes. As a new organization we have collaborated with a broad range of matrix partners and would like the following: 1. The Health and Human Services to offer grants and 2. Technical assistance that will help drive the goals of helping Health and Human Services Office of Minority Health. 3. Partnership with community-based organizations can encourage minority enrollment in health care careers. 4. To provide faith-competency training and 5. At this time State surveys on diversity in corporate America bracket women, various races, and all nonwhite males in one category titled Aminority,@ which is an imbalance and inaccurate representation of data. At CHAMPS we have taken the initial steps. We need help to achieve our mutual goals to improve health care outcomes and achieve diversity in health care. We can't do this all alone and we need your help. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you very much. We have a little bit of time before 11:45, we are going to try to work in three additional persons. I'd like at this time to call Dr. Josephine M. Kershaw, Lynn Pender, and Dr. Gilbert Parks. If we have time, we'll also hear from Roberta Cottman.

JOSEPHINE KERSHAW: Good morning. My name is Josephine Kershaw and I am on the faculty at Florida A&M University, Tallahassee, Florida. I would like to share my concern with you as a researcher who has to review grant applications that the barriers to successful funding of these grant applications that I have seen involves a need for 1. advocates for ethnic and minority populations in grant review panels and I mean by that not just sort of figure heads on the grant panels but those who actually speak out for minority populations and their applications [applause] because they may not be as polished as those who have successfully submitted applications before.

Second, there's also a need for grant reviewers not only for ethnic populations, but also from ethnic and minority populations who understand the diverse cultures and the needs within those cultures [applause]. Third, there's also a need for recognition of exploring nontraditional methods to obtain culturally competent data. For example, if there are cultures that are preliterate, it is not logical to expect to administer written surveys to those cultures, because they will not be gathering valid data, but perhaps obtaining qualitative data through door-to-door interviews and such would be a better method of obtaining data for these populations for which it is recognized there is a lack of data. In recognizing the disparities in ethnic populations it is important to get that baseline and get that initial information for those populations. I realize that these concerns and needs are probably not entirely new to the committee; however, much more attention is required in this area. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you Dr. Kershaw. Lynn Pender.

LYNN PENDER: Hello. I appreciate this opportunity to talk to you today. I will submit written testimony tomorrow. My name is Lynn Pender. I run an environmental justice organization in Baltimore called Youth Warriors. The two main things that I want to talk about today are 1. the impacts of health studies on populations at high risk for particular diseases (the instance that I am talking about right now is lead poisoning) and 2. the whole process of institutional review boards and the lack of inclusion of community-based organizations on them.

The issue that I want to bring to your attention is a study that was done by Kennedy Krieger Institute in Baltimore and the Johns Hopkins School of Public Health in the early 1990s that basically encouraged landlords with lead contaminated properties to recruit families with healthy children to move into the houses without letting the families know that their houses were lead contaminated. There are currently five cases, law suit cases currently going on in Baltimore right now addressing this issue.

The biggest problem is that Kennedy Krieger Institute, Johns Hopkins University, and other institutions around the country, we need these institutions to do research. Working with a community-based organization, I understand the importance and the prevalence of having their research. It's no doubt that they have provided wonderful information about lead poisoning that we would not have had otherwise; however, to use our children as human lead detectors, and that is basically what they did in this particular research project, it's just unacceptable. And what we (as a community) are saying is that it's time for boards like this and other Federal agencies (because this grant was funded by the EPA, it was also funded by HUD, it was also funded by private foundations with the thought that this was an institution that was seeking a community collaboration). It was a community collaboration on paper, but not in reality. And all too often that happens. So I stand here asking what can we do? [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Pender.

GILBERT PARKS: Good morning. I'm Gilbert Parks. I'm from Topeka, Kansas. I represent myself this morning. This is mainly because probably no organization I'm associated with often will accept some of the things I say. [Laughter] I really come before you this morning to mention three major points that I think the Committee can deal with in terms of public policy and that's what I am assuming that we are advising on this morning. Within HHS, there are specific entities in each section or department that deal with issues that we are speaking about this morning. They are highly underfunded by one principal that is written into the legislation. It says that each division may take 5 percent of their budget and build a staff to work on these issues. That needs to be changed to shall take 5 percent of their budget. And, I think the Secretary may be advised on that and a score card should be measured. It's whether we have the will to do that or not. We will only make progress when the

monies are appropriated by the people who can make things happen.

As long as all the individuals are underfunded, understaffed, all these issues will never be succeeded. I think that has been said here many times this morning. But, I want to emphasize, particular, specific policy.

The second thing I would mention is, because I do represent private practice in health care [inaudible] physicians this morning. Public policy cannot move toward forcing all private practitioners out of private practice, because you then de-empower all of these communities and force them on the institutions that are controlled by the same people that you all have been talking about this morning. And you create institutions for which all these individuals who once were empowered and can create their own institutions are now controlled by certain institutions that have all the characteristics that you spoke of this morning. [Applause] Therefore, I recommend to this Committee, highly recommend, that the United States Government stop supporting any institutional process or public policy that would disenfranchise and disempower the communities that you represent here this morning. Public policy is the key to this, in order to redistribute the millions of dollars, billions of dollars.

Last example in discussion: 10 billion dollars were sent for AIDS this last few years. Only a very small percentage was controlled by this community here, yet they have the largest percentage. I have a fear that the same thing is going to happen in this disparity issue. Billions of dollars will be appropriated. But the key issue is, who will control those dollars? We must control the number of dollars directly proportioned to the issue, from an administrative standpoint, not from the trickle-down standpoint. Because I always say to legislators form the prisons in terms of who owns the prisons proportionate to the population in those prisons. Let contracts for building prisons portioned to the population in those prisons. Nobody will make that kind of public policy, but we need to make that kind of public policy in regards to the issue of disparities in healthcare. Thank you. [Applause]

CHAIRPERSON STOKES: Thank you Dr. Parks. Roberta Cottman? Ms. Cottman is our last witness this morning.

ROBERTA COTTMAN: Thank you very much for the opportunity. I'm Roberta Cottman, Wayne State University, Detroit. I'd like to make several points. And, I hope I'm not repeating, as I came in late. We must make a difference in our talk and in our actions in regards to health and health care. That looking at health is all of the social and economic and emotional determinants that determine what our health care is. And by chance, if you have a problem, then you should have access to not only timely care, but appropriate care and continuity of care. And, this is where the system breaks down. Hello my friend [laughter]. We must look at prevention and therefore look

at the document of the Department of Health and Human Services. And, that is Healthy People 2010 that gave us the data, that gave us the direction, that gave us some strategies. A prevention agenda number one that everybody should have care through the life span and that means appropriate from infant mortality to long-term care. The second is that we should eliminate disparities. Not reduce, but eliminate health disparities. And, we need to look at the document and refer to it. I do not see it on the agenda. And, therefore, looking also at the Centers for Disease Control, there are nine preventable deaths in regard to disease states. And looking at those risk factor, the diabetes alone, if we just looked at prevention. And then nutrition, no nutrition, malnutrition, all kinds of nutrition leading to overweight and obesity, a huge problem in our young people. Environment, we cannot leave out respiratory disease in regards to pollution. Tobacco: Our communities must use that tobacco settlement money for health and health care. North Carolina, Tennessee, and Michigan are the only three States in which it is not used. And last, we talk about food, clothing, and shelter, nutrition. We cannot leave out water. Water is the most rapid commodity all over the world increasing in even designer water. But, if we don't have water, if we don't have clean water, if we don't have safe drinking water, if we don't have, for nutrition, you cannot live without water. [Applause]

CHAIRPERSON STOKES: Thank you very much Ms. Cottman. Ms. Cottman, with her testimony, we conclude the testimony before the Advisory Committee this morning. Let me, at this time, on behalf of the entire Committee express our appreciation to those of you who have appeared here and who have given testimony and for those of you who have not made a personal presentation, but who will also submit your written testimony to us. We urge you to do that. We would like to have your testimony and will listen to it. I really want to thank you for not only the substance and the quality of the presentations here this morning. But, also for the cooperation given us in permitting everyone to be able to get their presentations in on time. Seldom do you see this type of public cooperation. I really think we ought to give all of them a great big hand. [Applause]

You have been very helpful to us by giving us testimony. I want to thank our time keeper Olivia, here. She did an excellent job with that finger in the air [laughter and applause] and also Sheila Pack Merriweather who did such a great job with coordinating. Not only for these activities, but she keeps all of the Committee on its toes and keeps everything coordinated between us and does a marvelous job.