

# THE HEALTH CARE FAIRNESS ACT OF 1999

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HEARING  
BEFORE THE  
SUBCOMMITTEE ON  
HEALTH AND ENVIRONMENT  
OF THE  
COMMITTEE ON COMMERCE  
HOUSE OF REPRESENTATIVES  
ONE HUNDRED SIXTH CONGRESS  
SECOND SESSION

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# THE HEALTH CARE FAIRNESS ACT OF 1999

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THURSDAY, MAY 11, 2000

HOUSE OF REPRESENTATIVES,  
COMMITTEE ON COMMERCE,  
SUBCOMMITTEE ON HEALTH AND ENVIRONMENT,  
*Washington, DC.*

The subcommittee met, pursuant to notice, at 11:48 a.m., in room 2322, Rayburn House Office Building, Hon. Michael Bilirakis (chairman) presiding.

Members present: Representatives Bilirakis, Whitfield, Coburn, Greenwood, Brown, Waxman, Green, Strickland, Barrett, Towns, and Eshoo.

Staff present: Carrie Gavora, professional staff; Marc Wheat, majority counsel; Kristi Gillis, legislative clerk; and John Ford, minority counsel.

Mr. COBURN [presiding]. Let me, first of all, apologize to all those in the room and my fellow members for the tardiness for the beginning of this. The votes this morning did change our schedules and then the briefings on China in which a lot of members are involved could not be missed.

We are going to have opening statements and I am going to dispense and enter mine in the record.

[The prepared statement of Hon. Tom A. Coburn follows:]

PREPARED STATEMENT OF HON. TOM A. COBURN, A REPRESENTATIVE IN CONGRESS  
FROM THE STATE OF OKLAHOMA

Mr. Chairman, I am pleased to welcome Dr. John Harley from my home state of Oklahoma. Dr. Harley serves as both the Head of the Arthritis and Immunology Department at the Oklahoma Medical Research Foundation and as a Professor of Medicine at the University of Oklahoma Health Sciences Center, where I received my own medical degree. Since my congressional district includes the Cherokee Nation, the second largest Indian nation in the country, I am anxious to hear about his work concerning the Native American Biomedical Research Center at OMRF.

I am also pleased to welcome my friend and colleague J.C. Watts as well as the Surgeon General, Dr. David Satcher, whom I have the greatest respect and admiration for and have had the privilege of getting to know and work with over the past several years on numerous public health issues.

The majority of the patients I see in my medical practice tend to be women and ethnic minorities and the issue of health care disparities for any group is a very important issue for me, both as a practicing physician and a member of Congress. While there are numerous reasons for the disparities that exist, some have been created as a direct result of misguided federal policies. One obvious example is the federal response to HIV/AIDS.

Along with Commerce Committee Chairman Tom Bliley, last year I requested an investigation by the U.S. General Accounting Office (GAO) to determine if racial inequities existed within federal HIV/AIDS programs. The GAO found that "African Americans, Hispanics, and women are served by the Ryan White CARE Act in higher proportions than their representation in the AIDS population," yet "they generally receive less appropriate health care for their disease."



This disparity is a direct result of the CARE Act's inappropriate focus solely on AIDS, the end stage of HIV infection. The CARE Act does not recognize those with HIV who have not yet developed AIDS. Women, African Americans and Hispanics—all of whom have significantly higher HIV rates—are therefore largely ignored by this oversight.

States and cities with relatively new epidemics are not receiving the federal support they need to care for all of those in their communities that are infected. Because it may take ten or more years for someone infected with HIV to develop AIDS, it will therefore take more than a decade for the CARE Act to recognize the extent of the epidemic as it exists today.

The failure to recognize HIV has another significant negative impact on women and communities of color at the local level. Planning Councils which largely determine how funds will be spent and set care and service priorities are required by law to reflect the demographic make-up of the epidemic in an area. As long as only those with AIDS are represented, women, minorities and other groups that are being increasingly affected by HIV will be largely excluded from this decision making process and denied access to many of the available health care services.

In testimony submitted for this hearing, Ms. Loretta Davis-Satterla, the Director of Michigan's Division of HIV/AIDS-STD, states that "AIDS case surveillance alone does not accurately reflect the extent of the HIV epidemic among African Americans, women, adolescents and young adults." She notes that "in Michigan, confidential HIV reporting has been required by statute since 1989." And "as a direct result of having HIV case data available for planning efforts, current prevention efforts supported by the Michigan Department of Community Health emphasize racial/ethnic minorities, women and at-risk youth."

Davis-Satterla explains that "when seeking to address these issues, with the goal of achieving 100% access and 0% disparity, it is essential that systems are utilized that allow identification of emerging trends relative to race/ethnicity, gender and behavioral risk factors. Planning based on trends in HIV infection provides a more accurate assessment of the distribution of the infected population, the number of individuals in need of access to treatment, and the type of medical and support services required to meet client needs. In Michigan, HIV case reporting and the Uniform Reporting System have been effective tools in addressing the current epidemic by facilitating planning of appropriate prevention, early intervention and care services."

In addition to HIV/AIDS care services, the federal prevention policies have also disadvantaged women and minorities. This failure can be seen in the fact that the number of infected African Americans and women has continued to increase in recent years. Perhaps the single most tragic failure of the existing prevention policy was the decision to allow children, mostly African American and Hispanic children, to become hapless victims of HIV—despite the fact that the capability exists to virtually eliminate pediatric AIDS.

In 1994, it was discovered that administration of the drug AZT—now known as ZDV—during pregnancy and childbirth could dramatically reduce the chance that a child of an HIV-positive mother would be infected. Another study showed that HIV transmission from mother-to-child can be nearly eliminated when Cesarean section is coupled with ZVD at birth. A more recent study has found that even if treatment begins shortly after birth, transmission can still be considerably reduced.

Despite these medical miracles, a significant number of women are still not tested for HIV during their pregnancy and many children are being allowed to become needlessly infected with an incurable, devastating disease that will prematurely claim their lives. Half of these infected children will be die before their third birthday and nearly all will be dead by age 5 unless they are promptly diagnosed and receive proper medical treatment which can prolong and improve an infant's life.

Nearly all of the 382 children reported with AIDS last year—84 percent—were African American and Hispanic. Our government owes an explanation to the mothers and families of these children as to why they were allowed to become infected with a disease that could have been prevented.

I would expect that any legislation we consider this year to address the issue of health care disparities must ensure that not one more child is allowed to become infected by HIV and die of AIDS.

I also intend to introduce a bill to reauthorize the Ryan White CARE Act, the federal HIV/AIDS care program, which will address the issue of disparities in HIV/AIDS care. It will do this by ensuring increased involvement by all communities affected by the disease on planning councils and by better targeting of federal funds to underserved communities. I hope that every member of this committee would sign onto this bill to ensure increased access to life saving care for all Americans impacted by HIV, regardless of their race or gender.



Mr. COBURN. I will now recognize the ranking member, Mr. Brown for his opening statement.

Mr. BROWN. I want to thank my colleagues, Mr. Thompson, Mr. Lewis, Mr. Jackson and others for joining us today. I would also like to extend a special welcome to Mr. Satcher, who among his many accomplishments throughout his career, was first in his class at the Case Western Reserve University Medical School some not too many years ago in Cleveland, Ohio. Dr. Sullivan, it is nice to have you with us also.

I am a co-sponsor of the Health Care Fairness Act, as all the witnesses are today. This legislation makes sense. We need the research that H.R. 3250 fosters to make decisions about the health care system; we need the education 3250 facilitates to reduce disparities in health; we need the training 3250 supports to reduce disparities in health care.

It is as simple as that and as complicated as that. If I polled everyone in the room on the criteria that should be used to evaluate the U.S. health care system, my guess is the answers would not vary all that much. Most of us would mention access, quality, cost, the system should provide more Americans, all Americans access to high quality care at a reasonable cost. I hope equity would work its way into the formula.

A health care system that perpetuates significant and reversible racial, ethnic or socioeconomic disparities in health and life expectancy is not my idea of a good health care system. In a Nation like ours, one that is increasingly defined by the diversity of its population, it is my idea of a system on its way out.

The way we judge our health care system is not logical or is not explicit. If we actually use standards like access, quality, efficiency and equity to guide health care policy and health care spending, we would not need this legislation. Universal coverage would be the priority. Research and disparities in health care, strategies to minimize those disparities would be a priority.

Let us look at the way the U.S. health care system actually works. Forty-four million people are uninsured. Certain minority populations, especially Hispanics, are far more likely to be uninsured than white Americans. The Nation subsidizes health insurance for individuals fortunate enough to be employed by a firm that offers health coverage; their premiums are pre-taxed.

We also cover low income children and a few other discrete categories of very poor people and we provide incomplete but valuable coverage to the elderly. If you do not fall into one of those categories, tough luck.

The Nation funds enormous amounts of research, very little of it devoted to understanding why there are significant disparities in health and health care between populations in the United States, and even less of it devoted to doing something about those disparities.

Mr. Satcher did his best at CDC. Ed Towns and others on this subcommittee have done their best but it is changing much, much too slowly.

Over time, enough evidence has accumulated so that there is no doubt about it, there is significant disparities in health and health care. Minority populations, as we all know, have higher rates of



cancer, heart disease, diabetes, HIV AIDS and that is just a partial list.

Minorities have shorter life expectancies, higher infant mortality rates and higher incidence of premature death. Minorities are less likely to receive cancer screening and less likely to receive monitoring. Minorities are less likely to receive childhood and adult vaccinations, doctors are four times more likely to correctly identify a heart attack and hospitalize a patient if that patient is white. According to recent research, doctors are getting better at treating cancer pain unless you are a Hispanic or African-American.

We have a top notch health care system, what this Nation is spending money on, subsidizing health insurance for millions of working Americans and other select groups, financing groundbreaking research that fuels medical advancement throughout the world. What this Nation is spending money on is not wrong, but it is not 100 percent right either. We need to work on the system until it does not matter what your race is, what your ethnicity is, what your employment status is, you should still be a beneficiary of medical advancement and a recipient of the highest quality care this Nation has to offer.

The Health Care Fairness Act sets the stage for that system. I am thrilled the subcommittee is finally paying attention to this very important legislation.

Mr. COBURN. The gentleman from New York?

Mr. TOWNS. Thank you very much.

Also, let me thank the ranking member, Mr. Brown, for his outstanding work in this area. Also, I am delighted to see the former Secretary of Health, Dr. Sullivan, and Surgeon General Satcher and my colleagues, Mr. Thompson, Mr. Lewis, Mr. Jackson and Mr. Rodriguez.

Let me just say that we have undoubtedly made tremendous advances in the area of health in the last few years in the areas of treatment and new technology—gene therapy vectors, new antibiotics, surgeries, unborn children to reversed birth defects. Even with all these wonderful developments, there are still inequities in our health care system.

There is a growing mountain of evidence that not all patients with the same signs and symptoms are being treated equally under our system of care. There is compelling evidence that there are racial and ethnic health disparities and now is the time to address this issue.

A number of studies published in the New England Journal of Medicine, the Journal of American Medical Association by the Kaiser Family Foundation demonstrates the extent of racial and ethnic health disparities in our medical system. These studies range from decreased aggressive cancer care in blacks to perception of minority groups that they receive lower quality of health care.

We cannot continue to allow our health care professionals to treat patients differently because of the patient's ethnic background. That is unacceptable in the United States of America.

This complex problem suggests the need for a comprehensive answer and the answer is H.R. 3250, the Health Care Fairness Act. This bill addresses the issue of health disparities from a number of different and crucial vantage points. First and foremost, it estab-



lishes the center at the NIH to increase the breadth and depth of research in this area. I think it is of the utmost importance that a premiere research center such as NIH take a leadership role in addressing health disparities and aiding the transfer of research information to patient-friendly and useful data.

The bill also deals with the education of physicians across skill ranges to begin to highlight their biases and change them. These are only two of the points I wanted to highlight in this bill. Along with the comprehensive approach to this bill, I want to mention our community health centers and the important role they play in treating many of the patients who this bill will positively impact.

Our Nation's community health care centers provide care to over 7 million minorities each year. The culturally sensitive care provided at these health centers is delivered in an efficient and effective manner, leading to documented decreases in preventable illnesses and increased rate of childhood immunization and reduction in inappropriate usage of hospital emergency rooms and a dramatic drop in infant mortality rates to name just a few.

I think we should look at service delivery models such as community health centers are currently working to decrease these disparities. I also want to acknowledge again both our Surgeon General and the former Secretary of Health, Dr. Sullivan, now President of Morehouse Medical School on their leadership in the area of reducing health disparities.

I am looking forward to the enlightening testimony coming first, from our colleagues and others who will be giving us information as to why we might need to move very rapidly with H.R. 3250.

On that note, I yield.

Mr. COBURN. Thank you.

Recognize the gentleman from California.

Mr. WAXMAN. For years this subcommittee has led congressional efforts to eliminate the persistent health disparities in communities of color. I hope that today's hearing marks a renewal of these efforts to improve access to care and expand research of importance for all Americans.

The last time we addressed this issue was in the 103d Congress when Senator Kennedy and I sponsored the NIH Revitalization Act which established the NIH Office of Research on Minority Health and the Minority Health Improvement Act, which would have established national priorities in improving the health status of minorities.

I am pleased we are going to hear from Surgeon General Satcher and Mr. Louis Sullivan to testify to our Government's current and past efforts. They can attest to the progress which has been made.

As one measure of the long road ahead of us, I want to read two conclusions from the Institute of Medicine's recent report on the "Unequal Burden of Cancer" on communities of color. "One, the research priority-setting process at NCI and NIH fails to serve the needs of ethnic minorities and medically underserved groups." "The committee found little evidence that NCI or NIH has undertaken a thorough assessment of training programs to determine whether these programs are producing adequate numbers of ethnic minority researchers in all appropriate cancer research fields." I think these conclusions speak volumes about the need for congressional action.



The Administration is certainly not idle. I know the NIH has convened an internal working group on health disparities but I am certain every member and witness here today will agree that there is little danger of doing too much for Americans who have historically had to settle for too little attention and too few resources.

As a co-sponsor of H.R. 3250, I believe this bipartisan legislation would be of enormous help. I strongly encourage you, Mr. Chairman, to schedule a markup for next week or at the earliest possible date. The remaining time in the session is very short but the need for health care equity is very great.

Mr. COBURN. I thank the gentleman.

Ms. Eshoo?

Ms. ESHOO. Thank you and good afternoon everyone.

Thank you for holding this very important hearing on H.R. 3250. I think the legislation really marks a historic effort to improve the health of minorities across our country.

I want to commend our colleague, Congressman Bennie Thompson, for introducing the bill. It is a solid piece of work and it is thoughtful. I have gone over it section by section and I salute you for the work you have done on this and also our distinguished Chairman for taking the first important step toward the enactment of this legislation by holding today's hearing.

In February 1998, President Clinton challenged our Nation to an ambitious goal. By the year 2010, we must eliminate longstanding disparities in health status experienced by all racial and ethnic minority populations in our Nation. His challenge followed a series of disturbing findings that despite significant improvements in the health of Americans, minority Americans continue to suffer from certain diseases at up to five times the rate of white Americans.

Here are some examples. African-American men under 65 suffer from prostate cancer and heart disease at nearly twice the rate of whites. Vietnamese women suffer from cervical cancer at nearly five times the rate of whites. Latinos have two to three times the rate of stomach cancer. Native Americans suffer from diabetes at nearly three times the average rate while African-Americans suffer 70 percent higher rates than white Americans.

That is astronomical when you stop and think about that. I want to repeat that. African-Americans suffer 70 percent higher rates than white Americans in that area.

We have to close these gaps. Much more needs to be known about why minority populations are experiencing such desperately high rates and other diseases that we really can target much needed resources toward eliminating the disparities.

This legislation tackles the problem by establishing a new National Center for Research on Minority Health and Health Disparities at NIH which I am very fond of calling our National Institutes of Hope. I think if we can build this legislation into our National Institutes of Health, it really is going to give hope to so many Americans across our country.

The bill also authorizes the Agency for Health Care Research and Quality to conduct and support research which is a very, very important part of this effort. We have to learn more so that we can do better.



I am especially excited about the provisions in the legislation aimed at education and outreach surrounding minority health. Too few health care professionals today are really aware of the special health care needs of minority populations or even how to provide them. Under this bill, grants will be available to medical schools and nursing schools to incorporate the cultural awareness programs in that very special education.

Community and rural health centers will receive incentive payments to develop innovative strategies to reduce ethnic health disparities for health professionals.

Finally, the bill directs the Secretary to develop a system to evaluate the performance of Medicare and Medicaid and how they are doing.

I want to welcome the very, very distinguished people here to testify today. We are fortunate to have the Surgeon General, Dr. Satcher, and to hear his enlightened views and a very warm and special welcome to the former Secretary of Health and Human Services, Dr. Sullivan. He has participated in more than one conference I have attended on health care.

To each and every one of you, it is not very often we come into this hearing room and I see a very long line out in the corridor, so this is an issue that I think all Americans care about. This Congress can do something about it and I hope after the hearing we will move to markup and to the floor.

Thank you.

Mr. COBURN. I just want to make a couple of comments.

Much of what I have heard in our opening statements, as a practicing physician, I agree with. There is a tremendous disparity but not all is despair. There are lots of minorities that get great care. I think it is very important that we focus on those who do not because there are lots of non-minorities who do not get great care too.

What we want to do is keep in balance. One of your statements, even though it is meant, in a lot of communities—Muskogee, Oklahoma—you do not just have tough luck if you do not have health insurance because the physician community, the hospital community, the nursing community, the pharmacist community work to take care of the people. That does not mean they are all taken care of as great as we can.

I want to make sure as we hear our testimony and put our words in the record that where credit needs to be given, there are a lot of communities, communities of color and noncolor, that are doing a great job taking care of those folks that do not have what we want everyone to have.

For us to say that the problem is without that light, there is light. We just have to do a whole lot better and there are a lot of people who we need to care for that are not being cared for today.

[Additional statements submitted for the record follow:]

PREPARED STATEMENT OF HON. MIKE BILIRAKIS, CHAIRMAN, SUBCOMMITTEE ON  
HEALTH AND ENVIRONMENT

My thanks to all of the witnesses who have taken the time to testify at today's hearing on H.R. 3250, the Health Care Fairness Act. The purpose of this legislation is to identify and rectify health disparities that occur among minorities.

I am especially pleased that upon the rescheduling of this hearing, the Administration was able to send three witnesses, including Dr. Satcher. Hopefully, this



hearing will provide a clear picture of the Administration's perspective on the Health Care Fairness Act and proposals related to the Office of Minority Health in particular. I would ask unanimous consent at this point to enter into the record a letter of support from the Association of Academic Health Centers in support of H.R. 2391 and H.R. 3250, bills to elevate the Office of Research on Minority Health at the National Institutes of Health.

In preparing for this hearing, I have reviewed with concern the health disparities that persist between some minority groups and the non-Hispanic white population. Hepatitis C, heart disease, diabetes, lupus, lung cancer, and cervical cancer are but a few of the diseases that disproportionately affect minorities in this country.

I was alarmed by the very significant disparities found in those infected with HIV, the silent killer of so many Americans. I would ask unanimous consent to enter into the record the testimony of Mr. Thomas Liberti, Chief of the Bureau of HIV/AIDS for the Florida Department of Health. Mr. Liberti could not join us today in person due to a back injury, and we all wish him a safe recovery.

Likewise, Hepatitis C has also been identified at significantly higher rates among minorities. For example, available data indicates that the rate of Hepatitis C infection among African-Americans is 2 to 3 times higher than the general U.S. population.

Of course, some health care providers—including community health centers—are acutely aware of this problem from their day-to-day work on the front lines of medicine. Community health centers are the leading providers of health care to over 7 million minorities in medically under-served urban areas each year. As a strong supporter of their vital mission, I believe it is important to recognize the critical role they play in attempting to reduce minority health disparities. I would ask unanimous consent to enter into the record a statement on these issues by the National Association of Community Health Centers.

We have made every attempt to accommodate a broad variety of witnesses today, and I would appreciate the Subcommittee's help in managing our time. Again, I want to welcome all of our witnesses and thank them for their time and effort in addressing this concern.

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PREPARED STATEMENT OF HON. CLIFF STEARNS, A REPRESENTATIVE IN CONGRESS  
FROM THE STATE OF FLORIDA

Thank you, Chairman Bilirakis, for holding this important hearing. I look forward to hearing from our distinguished witnesses, which include several of our colleagues as well as our current Surgeon General David Satcher and former Secretary of Health and Human Services, Dr. Louis Sullivan.

H.R. 3250 addresses how we can improve access to health care for minorities. This goal would be achieved in the bill in several important ways. First, it would establish a New Center for Research on Minority Health and Health Disparities at NIH. This center would award grants for research in areas that are currently under-served.

In conjunction with this the Agency for Health Care Research and Quality would conduct outcomes research so that we can identify why such disparities occur. This would be coupled with data collection relating to the effects of race and ethnicity on access to health care. We need to know what the current roadblocks are before we can bridge the gap.

This information will help to address why there is such a higher rate of heart disease, diabetes and cancer in the African-American, Hispanic and Native American communities than in other ethnic populations. I was particularly interested in the testimony submitted by Dr. Fridell on the higher rate of prostate cancer among African-Americans than white men. Dr. Fridell also points out that we need to find out why Chinese American men have such low rates of prostate cancer compared to African American men.

We need to look at variety of critical issues when evaluating why certain groups in our population have higher rates of cancer, diabetes and cardiovascular disease. More importantly, we need to look the roles that diet, customs, and environmental factors might play in the higher incidences of certain diseases in our minority communities.

There is one other area that merits discussion and that is the role genetics play in why certain diseases strike some and not others. In that regard, the new area of NIH research opportunity "Genomics" is one of the most exciting and promising developments in molecular medicine. Once the map of the normal function of human genes is made available, which is imminent, we will then be able to make comparisons with our own unique genetic blueprint. This will herald a new area of computer



collaboration with molecular medicine to develop a “DNA Chip,” transferring the functions of the human genome to a computer chip to be run for comparison for diagnostic and treatment purposes against our own genetic map. The software and hardware will need to be developed by the cooperative efforts of genome biologists, mathematicians and engineers to make the new field of Genomics a reality. We must ensure that our minority communities are not left out of this important aspect of future research efforts. It could very be a key to finding the answers to the many questions we have about why certain populations are more prone to certain types of diseases.

Thank you, Mr. Chairman, and I look forward to hearing our distinguished group of panelists.

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PREPARED STATEMENT OF HON. BARBARA CUBIN, A REPRESENTATIVE IN CONGRESS  
FROM THE STATE OF WYOMING

I think the intent of this bill is admirable. We all want equity in the health care system when it comes to access to services, availability of health insurance, and fair treatment for ALL patients.

Studies show us that disparities do exist within the health care system when it comes to race and ethnicity, and that concerns me. But substantial inequities in health care can also be found between males and females, children and adults, and urban versus rural areas.

What I question in this legislation is whether or not we’re going too far, too fast with something that could very easily wind up to be another link in the chain of big government.

This bill creates an entirely new “Center” to study the health of minority populations. How exactly does this “Center” fit within the structure of NIH? This is not clear to me. It is, in essence, its own institute within NIH but it would receive its funding outside of the HHS or NIH budget allocation. This amounts to earmarking federal dollars to a “Center” with, correct me if I’m wrong, a rather unique status while other NIH institutes are forced to fight for their dollars in the NIH allocation???

To me, this essentially provides a carve-out for this “Center,” perhaps to the detriment of other NIH institutes. And where does the Administration stand on this bill? We don’t even know that.

Have we reached that point in time when the only answer to the problems facing the health of minority populations is to create another government program that will most assuredly cost billions of dollars to the American taxpayer??

I’m not convinced that we’ve reached that point and that’s precisely why I’m here today. I look forward to hearing from our witnesses today and hope they can shed some light on this issue.

Thank you, Mr. Chairman, and I yield back the balance of my time.

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PREPARED STATEMENT OF HON. TOM BLILEY, CHAIRMAN, COMMITTEE ON COMMERCE

I’m pleased that the Subcommittee is holding this hearing today on HR 3250, the Health Care Fairness Act. This legislation seeks to enhance research and education to address disparities in health care for minorities.

African Americans have a 70 percent higher rate of diabetes than whites. Hispanics suffer at a rate nearly double that of whites. African Americans have a cancer death rate about 35 percent higher than that for whites. Vietnamese women suffer from cervical cancer more than 5 times the rate of white women. We need to know why this is the case and I hope today’s hearing will help.

I’m particularly pleased that Dr. Anne Peterson, the Commissioner of Health with the Commonwealth of Virginia will be here today to testify.

The State of Virginia began mandatory reporting of HIV back in 1989. Collecting this data, as you will hear from Dr. Peterson, has had a positive impact on Virginia’s ability to identify and treat people with HIV.

This Committee is looking into reauthorizing the Ryan White CARE Act this year and I think it is timely to look at how minority populations are currently impacted by the way the Ryan White Act distributes funds.

I’m also interested in learning more about minority health professional education programs. GAO reported in the past that there have been some problems ensuring that funds allocated for minority health education are adequately targeting the minority health professionals they were designed to help.

I hope as we consider enhancing programs for minority populations, we make a full assessment of the programs that exist today, how they are working in meeting



their goals and how they will coordinate with the new programs proposed in this legislation.

While I understand that the Administration does not have an official position on this legislation yet, I'm hopeful that the Administration will be able to provide us with their position soon.

I thank the Subcommittee Chairman for holding this hearing. And I welcome all our witnesses today. I appreciate so many of my colleagues taking time out of their day to testify at this hearing and I look forward to receiving all the witnesses testimony.

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PREPARED STATEMENT OF HON. TED STRICKLAND, A REPRESENTATIVE IN CONGRESS  
FROM THE STATE OF OHIO

Mr. Chairman, I want to thank you for holding this hearing today on what I think is one of the most important and most overlooked issues in health care. I am thankful that we are pursuing this issue, and I certainly hope that the subcommittee and the full committee will move this legislation forward as quickly as possible.

I am struck and saddened by the findings reported in HR 3250: that for almost every serious or life-threatening disease, minorities are at increased risk for contracting that disease and dying from it. Cancer, infant mortality, AIDS, cardiovascular disease, hypertension, diabetes and HIV all confront minority ethnic groups with greater ferocity than the white population. And we know some of the reasons for this deadly disparity: lack of health insurance, low income, lack of access to primary care physicians and specialists, geographic isolation, low literacy levels, and the list goes on.

These are some of the same demographic characteristics that describe the rural Appalachian population that I represent, and, not surprisingly, many of the same disparities in health status exist among the poor, white population of Appalachia. In fact, research done in Kentucky shows that, among the Appalachian white population, incidence rates for cervical cancer and lung cancer are significantly greater than the rates for those cancers among the white population as a whole. In fact, the cancer incidence rates among white Appalachians in Kentucky is much more closely aligned with the rates for black individuals in Kentucky.

That this disparity exists at the end of the twentieth century is cause for grave concern and immediate action.

But I am concerned that our federal institutions charged with health care research have not been doing all they can to eradicate this disparity. Clearly, this is a problem that has many complex causes and even more complicated solutions, a problem that cannot be solved overnight. But I have read with great concern some of the discoveries of the Institute of Medicine's report, "The Unequal Burden of Cancer." In this study, the IOM reports that "while NCI (National Cancer Institute) reports that it allocated \$124 million to research and training programs relevant to ethnic minority and medically underserved groups in fiscal year 1997, the committee believes that the actual figure allocated for these groups is only slightly more than \$24 million, or approximately 1% of the total NCI budget."

I hope that this hearing on HR 3250 will be the beginning of a process where we will enact legislation that will correct these inequities for all Americans.

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PREPARED STATEMENT OF HON. JOHN D. DINGELL, A REPRESENTATIVE IN CONGRESS  
FROM THE STATE OF MICHIGAN

Mr. Chairman, thank you for holding today's hearing on the important issue of disparities in health care amongst the diverse ethnic groups that comprise our nation. I regret that floor action on the Conservation and Reinvestment Act precludes my delivery of this statement in person.

America's health care enterprise has three responsibilities: 1) providing preventive health services and treating disease; 2) conducting biomedical research; and 3) training health care professionals to meet the needs of today, and anticipate the needs of tomorrow. Unfortunately, minority populations have been unequally and inadequately recognized and represented in all three health-related activities. H.R. 3250 makes tremendous strides on all three fronts.

As you are about to hear from the Surgeon General, Dr. David Satcher, "as we look at the state of minority health in America, we are really looking at the future of our nation's health." The future of our nation's health will be influenced, in large measure, by advances in genetic medicine, a subject that will resonate through much of the expert testimony we will hear today. The human genome project has already shown us that there is greater genetic variability within ethnic groups than



between ethnic groups. Research is now on the brink of unlocking the keys to ethnic differences in susceptibility and resistance to such common health problems, such as heart disease, diabetes, cancer, and stroke. These discoveries will allow us to target screening, treatment, and prevention more effectively, thereby minimizing health disparities.

As the world's leader in biomedical research, we must supplement our new technologies with a workforce of culturally competent physicians and health professionals. H.R. 3250 addresses this by calling for the development of educational tools and programs that will sensitize health professionals to a variety of health belief systems and enhance provider communication skills in areas ranging from simple health history-taking and education to recruiting and enrolling members of minority groups in appropriately designed clinical trials.

This year's census, for the first time in our nation's history, is expanding the available data on the ethnic origins of Americans from the five categories formerly used. I am optimistic that the availability of this new, expanded data about target populations will help close the information gaps we will hear about from Dr. Fridell on behalf of the Institute of Medicine, as well as other witnesses. The Institute of Medicine's study, "The Unequal Burden of Cancer: An Assessment of NIH Research Programs for Ethnic Minorities and the Medically Underserved," provides a compelling brief for legislation such as H. R. 3250.

This hearing also provides an opportunity to thank our nation's community, migrant and homeless health centers, along with the other organizations that comprise America's primary healthcare safety net, for the important role they play in providing culturally-sensitive health care to over seven million minority individuals. Without this important resource, many of our nation's poorest citizens would have no access to health care, and the disparities we are discussing here today would be even worse.

Last year I fought hard to have the Balanced Budget Refinements Act include some relief for community health centers from the phase-out of the Medicaid cost-based reimbursement, but the job is only partially done. One way to sustain the vital safety net the community health centers provide to minority communities would be for this Committee to pass H.R. 2341, the Safety Net Preservation Act, which assures them a stable Medicaid funding system. I hope this can be accomplished this session.

In closing, I urge us to move forward with H.R. 3250. This legislation will strengthen the health care safety net for minority residents, their families, and underserved communities, by translating the enhanced research discoveries provided for in this bill into improved health care outcomes. Moreover, it is a bold step forward in marking the next decade with the highest achievable level of health care fairness in primary medical care and treatment, biomedical research, health professional education, and public awareness, for all citizens.

Mr. COBURN. With that, I would like to recognize our co-members in the House and the Honorable Bennie Thompson.

Mr. THOMPSON. Thank you, Mr. Chairman.

I would like to compliment you and this committee for conducting this hearing. It is obviously the first step in the right direction to address the health care inequities in this country.

I also want to compliment Mr. Lewis, Mr. Jackson, Mr. Watts and other members who have also co-sponsored this legislation. It is long overdue. As you will hear from my colleagues, and as you have heard from my esteemed members of the committee, we have a problem. This is America, this is the greatest country in the world.

The statistics quoted to you earlier today should cause all of us great concern. We can put people on the moon, we can do a number of things, but yet we have absolutely too many people of color suffering and dying needlessly in this country. For that reason, we offered this legislation and feel that reasonable people will, in fact, support it.

I can give you all the demographics but we know the story. We have to fashion and craft a solution. We see this legislation as one effort in crafting that solution.



The district I represent has 24 counties. All 24 counties I represent are medically underserved. We need help. This legislation addresses that and I look forward to the debate and discussion as we move this legislation forward.

Mr. COBURN. The gentleman from Georgia, Mr. Lewis.

**STATEMENT OF HON. JOHN LEWIS, A REPRESENTATIVE IN  
CONGRESS FROM THE STATE OF GEORGIA**

Mr. LEWIS. Thank you, Mr. Chairman.

I want to commend you, Mr. Chairman and members of the committee, for holding this hearing on such an important piece of legislation, H.R. 3250, the Health Care Fairness Act. I also want to commend Representatives Watts, Norwood, Thompson, Jackson, Rodriguez and Underwood for their commitment to making this bill a top priority. They are my friends and they are my colleagues and they care. I am glad to be here with them today.

I especially want to thank Dr. Sullivan and his staff and the many others concerned about minority health for all of the help they have given me and my staff in developing and promoting this legislation.

As a member of the Ways and Means Subcommittee on Health I have long been committed to eliminating health disparities. It is my hope that with today's focus on H.R. 3250, we can move quickly to eliminate those disparities. We all know how important this issue is.

Over the past few decades we have made great advances as a Nation in science and medicine. However, all of our citizens have not shared in the benefits of these advances. Minority populations have higher rates of death from cancer and health disease, as well as a higher rate of diabetes and other severe health problems. In fact, in many instances, minorities are not offered or given access to treatment. That is why we introduced the Health Care Fairness Act, a bipartisan bill supported by members of the Hispanic Caucus, the Asian Pacific Island Caucus and all members of the Congressional Black Caucus.

H.R. 3250 is also supported by the American Hospital Association, the National Medical Association, the National Asian Women's Health Organization, the Association of Minority Health Professional Schools, Association of Black Cardiologists, American Association of Medical Colleges, National Association of Community Health Centers, and many other organizations.

The Health Care Fairness Act includes an increased commitment to research minority health, improved data systems, culturally sensitive health care delivery and public awareness of the existence of minority health disparities.

We must make the commitment, the necessary commitment to eliminate minority health disparities. We must do it for the sake of not just the minority community but for the sake of our Nation. By focusing attention and Federal resources on this problem, the Health Care Fairness Act gives us a chance to bridge the health care gap.

Mr. Chairman and members of the committee, I ask for your commitment and your help to not only mark up H.R. 3250, but to pass this bill before the end of the 106th Congress. I look forward



to working with you in a bipartisan manner to make sure we pass H.R. 3250.

Thank you very much.

Mr. COBURN. Mr. Jackson?

**STATEMENT OF HON. JESSE L. JACKSON, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ILLINOIS**

Mr. JACKSON. I want to thank you for the opportunity to discuss with you the issue of minority health research at NIH. I am very pleased to be joined by my colleagues, Mr. Rodriguez, Mr. Underwood, Mr. Lewis and Mr. Thompson, on this panel to share ideas and concrete steps this Congress may take to address health disparities in this country between blacks and other ethnic minorities in the general population.

In this time of national economic prosperity and in particular, double digit growth for the National Institute of Health, Chairman Porter has set a single goal of increasing appropriations for NIH by 15 percent every year.

I am disappointed to report that the health status gap among blacks and other underserved populations is getting worse and not better. In my view, the National Institute of Health could, and should, be doing more to address health care needs of all Americans.

At the beginning of the 106th Congress, I was very pleased to be appointed to the Appropriations Committee and to its Labor, Health and Human Services and Education Subcommittee. Congressman Lewis Stokes of Ohio made gigantic steps and strides in improving minority health during his long and distinguished service on the panel. I hope to make a similar contribution.

One of the many benefits of serving on the subcommittee is the opportunity to carefully review the program activity and priorities of the Institute and to question the health care professionals and researchers that carry out this vital work.

In fact, the subcommittee held more than 40 hearings just this year alone and about 20 half-day sessions on which those hearings were dedicated to the oversight of NIH. I was privileged to attend almost all of those sessions this year as well as last year.

In January 1999, I had the privilege of meeting with Mr. Louis Sullivan, the former HHS Secretary and current President of the Morehouse School of Medicine. He shared with me testimony he gave before the Senate Labor Health and Human Services Appropriations Subcommittee concerning the Institute of Medicine's report that demonstrated a disturbingly low level of support for cancer research among minorities through the National Cancer Institute.

The cornerstone recommendation made by Dr. Sullivan in his testimony was to elevate the existing NIH Office of Research on Minority Health to Center status. What became increasingly clear across my inquiry at NIH was that the problem was not specifically centered in the National Cancer Institute, that amongst its 23 institutes, three centers and three offices, a general lack of coordination on these fundamental problems was clear and existed.

He contended that the existing structure in NIH did not adequately address or prioritize the issue of health disparities. After



asking scores of questions to the NIH Director and the Directors of the Institute and Centers during last year's hearings about these disparities, I became more convinced than ever that Dr. Sullivan was right, the Office of Research on Minority Health needed to be elevated to center status.

Consequently, I worked with Dr. Sullivan and other health care professionals to fashion a bill which I also support with Congressman Thompson and Congressman Lewis. The product of that bill, H.R. 2391 or Title I of 3250 which I introduced on June 30, 1999.

In plain terms, the bill provides the Director of the Center a seat at the table when NIH Institutes and Center Directors meet to discuss NIH policy and priorities. Presently, the Office of Research on Minority Health, when all of the Directors and Institutes meet, is not even in the room. They do not have a seat at the table to coordinate across the 23 Institutes, three Centers and three Offices, general coordination on these critical issues. The current Director does not attend these meetings.

Second, calls for health status disparities to be prioritized at NIH through the establishment of an NIH-wide strategic plan for health disparities with the Center playing the key role in that strategic plan.

Third, it establishes a grantmaking authority for the National Center which the office presently does not have. That is, researchers who might pursue issues such as health disparities and diabetes, cancer research or any other necessary and needed form of study, there presently is no grantmaking authority in that office to encourage researchers to study these various disparities.

Right now, the office director cannot spend his own budget unless an Institute Director allows him to fund a grant through his or her institute. This is unacceptable.

Mr. COBURN. Can you summarize, Mr. Jackson?

Mr. JACKSON. I am just one paragraph away, sir.

Fourthly, H.R. 3250 provides institutional support for those minority health professional schools which have a history and mission to serve and train minority health professionals and conduct research on health disparities. If we are ever going to solve the problem of health disparities, institutions which have a mission to solve these problems must be strong and viable.

I urge the subcommittee to move forward on legislation that would elevate the Office of Research on Minority Health to a Center. Elevating this office would better coordinate these efforts at NIH and therefore, save lives and families from being strapped by illness and anguish.

Together we can ensure that health care needs of all Americans are adequately addressed.

Thank you, Mr. Chairman, Ranking Member Brown and members of the subcommittee for this opportunity to present my views. [The prepared statement of Hon. Jesse L. Jackson, Jr. follows:]

PREPARED STATEMENT OF HON. JESSE L. JACKSON, JR., A REPRESENTATIVE IN  
CONGRESS FROM THE STATE OF ILLINOIS

Mr. Chairman, Ranking Member Brown and Members of the Subcommittee, thank you for the opportunity to discuss with you the issue of minority health research at the National Institutes of Health (NIH). I am very pleased to join my colleagues on this panel to share ideas and concrete steps this Congress may take to



address the health status disparities in this country between blacks and other ethnic minorities and that of the general population.

In this time of national economic prosperity, and double digit growth for the National Institutes of Health, I am disappointed to report that the health status gap among blacks and other underserved populations is getting worse, not better. In my view, The National Institutes of Health could and should be doing more to address the health care needs of all Americans.

At the beginning of the 106th Congress, I was very pleased to be appointed to the Appropriations Committee and to its Labor, Health and Human Services, and Education Subcommittee. Congressman Louis Stokes of Ohio made gigantic strides in improving minority health during his long and distinguished service on the panel, and I hope to make a similar contribution.

One of the many benefits of serving on the subcommittee is the opportunity to carefully review the program activity and priorities of the institute and to question the health care professionals and researchers that carry out such vital work. In fact, the Subcommittee held more than 40 days of hearings just this year, about 20 half-day sessions of which were dedicated to the oversight of NIH. I was privileged to attend almost all of those sessions this year as well as last year.

In January of 1999, I had the privilege of meeting with Dr. Louis Sullivan, the former HHS Secretary and the current President of Morehouse School of Medicine. Dr. Sullivan shared with me the testimony he gave before the Senate Labor-HHS Appropriations Subcommittee concerning an Institute of Medicine Study (IOM) that demonstrated a disturbingly low level of support for cancer research among minorities through the National Cancer Institute. The cornerstone recommendation made by Dr. Sullivan in his testimony was to elevate the existing NIH Office of Research on Minority Health to "Center status." He contended that the existing structure at NIH did not adequately address or prioritizing the issue of health disparities.

After asking scores of questions to the NIH Director and the Directors of the Institutes and Centers during last year's hearings about these disparities, I became more convinced than ever that Dr. Sullivan was right—the Office of Research on Minority Health needed to be elevated to "Center" status.

Consequently, I worked with Dr. Sullivan and other health care professionals to fashion a bill that would do just that. The product of those efforts is H.R. 2391, which I introduced on June 30, 1999. I am pleased to report that this bill has 87 bipartisan co-sponsors including Reps. Charlie Norwood, Nathan Deal, Sherrod Brown and Ed Towns of this subcommittee.

The bill, in plain terms would:

1) Provide the director of the Center a seat at the table when NIH Institutes and Center directors meet to discuss NIH policy and priorities.

Currently the director of the office does not attend those meetings.

2) Calls for health status disparities to be prioritized at NIH through the establishment of an NIH-wide strategic plan for health disparities, with the Center playing a key role in the strategic plan.

3) Establishes direct grant making authority for the National Center, guided by the work and scientific expertise of a national advisory council.

Right now the office director can't spend his own budget unless an Institute director allows him to fund a grant through his or her Institute.

4) Provides institutional support for those minority health professions schools which have a history and mission to serve and train minority health professionals and conduct research on health status disparities. If we are ever going to solve the problem of health disparities, institutions which have a mission to solve these problems must be strong and viable.

Mr. Chairman, I urge this Subcommittee to move forward on legislation that would elevate the Office of Research on Minority Health to a National Center. Elevating this office will help to save more lives and families from being sapped by illness and anguish. Together, we can ensure that the health care needs of all Americans are adequately addressed.

Thank you Mr. Chairman, Ranking Member Brown and members of the Committee for the opportunity to present my views.

Mr. COBURN. Mr. Underwood?

#### **STATEMENT OF HON. ROBERT A. UNDERWOOD, A DELEGATE IN CONGRESS FROM GUAM**

Mr. UNDERWOOD. Good afternoon, Mr. Chairman, Ranking Member Brown, distinguished members of the committee.



Thank you for the opportunity to speak before you today on a matter of great importance to us in this room, our health. I am here in my capacity as Chairman of the Congressional Asian Pacific Caucus and join in strong support with other members of this panel to urge the committee's support of H.R. 3250.

The Asian American-Pacific Islander community is the most ethnically and racially diverse community in our country. AAPIs are comprised of both immigrant populations as well as indigenous populations from the Pacific Islands. Census data reports that Asian American-Pacific Islander community is the fastest growing community in our country today. We can expect to grow from a population of about 10 million or 5 percent of the total U.S. population to 10 percent by the year 2050.

Asian Americans and Pacific Islanders are often labeled as the model minority with health or social problems. This is a myth and a gross misrepresentation of the situation. Within this population alone, there exists divergent economic and academic achievement rates and ethnically and racially diverse cultures.

Large subpopulations of East Asians and South Asians often skew the reality for small sub populations of Southeast Asians and Pacific Islanders.

Recent Department of Health and Human Services data shows that AAPI has experienced the highest rates of tuberculosis and Hepatitis B in the country. In fact, cervical cancer incidences are five times higher for Vietnamese women. Liver cancer among Vietnamese is found to be 11 times higher than the general population. Native Hawaiians have the second highest mortality rate to lung cancer. Diabetes affects tomorrow's natives of Guam at five times the national average and infant mortality rates in the U.S. and insular Pacific areas are more than double the national average.

It is clear that the face of America has become increasingly diverse as its minority populations continue to grow and as our minority populations increase, so will the complexity of our health situation, which means that we need innovative approaches to deal with this issue.

The Health Care Fairness Act lays out a plan to reducing racial and ethnic disparities in health care and health care outcomes by elevating the Office of Research on Minority Health to create a center for health disparities research at the National Institutes of Health. We will significantly increase the support of research on health care disparities, improving data collection relating to race and ethnicity and funding major increases in minority medical training and curriculum development. The NIH needs a strong and effective coordinating body to focus research and awareness on the health care needs of all minorities.

There is also much room for improvement in the methods of data collection. Within the Asian American and Pacific Islander community there exists scant local and Federal data to document the needs of our communities. It is only with the emergence of more recent and improved data collection that we are beginning to realize the unique needs of the AAPI communities.

The Health Care Fairness Act represents a comprehensive, bipartisan effort to effectively address the health care needs of all our communities. As Chairman of the Congressional Asian-Pacific



Caucus, I strong urge your support and commitment to bridge the gap which denies minority Americans from receiving fair access to health care, health care that has meaning in their cultures and their lives, and other quality of life services.

I join with my colleagues on this panel to urge you to move forward with this bill.

Thank you very much.

[The prepared statement of Hon. Robert A. Underwood follows:]

PREPARED STATEMENT OF HON. ROBERT A. UNDERWOOD, A DELEGATE FROM GUAM

Good afternoon, Chairman Bilirakis and Members. Thank you for an opportunity to speak before the Committee today on a matter of great importance to many of us in this room—our health. I am here in my capacity as Chairman of the Congressional Asian Pacific Caucus and join in strong support with my fellow colleagues on this panel to urge the Committee's support for H.R. 3250, the Health Care Fairness Act.

The Asian American and Pacific Islander (AAPI) community is the most ethnic and racially diverse community in our country. It is also the most heterogeneous community. AAPIs are comprised of both immigrant populations (including East Asians from Japan and China, Southeast Asians from Vietnam, Cambodia, and Laos, and South Asians from India) and indigenous populations of Pacific Islanders (Native Hawaiians, Chamorros from Guam and the Commonwealth of the Northern Mariana Islands, and American Samoans). Census data reports the Asian American and Pacific Islander community is the fastest growing community in our country today. We expect to grow from a population of 10.4 million or 5 percent of the total U.S. population to 10 percent by 2050.

Asian Americans and Pacific Islanders are often labeled as the "model minority" with few health or social problems. This is a myth and a gross misrepresentation of AAPIs. Within this population alone, there exists divergent economic and academic achievement rates and ethnic and racially diverse cultures. The large subpopulations of East Asians and South Asians often skew what the reality is for the smaller subpopulations of Southeast Asians and Pacific Islanders, who traditionally do not parallel the same rates of the larger subpopulations.

Department of Health and Human Services data shows:

- AAPIs experience the highest rates of tuberculosis and Hepatitis B in the country;
- Although new cancer cases declined for all racial and ethnic groups from 1990 to 1995, the rates for AAPI women remained level;
- In fact, cervical cancer incidences are 5 times higher for Vietnamese women;
- Liver cancer among Vietnamese is found to be 11.3 times higher;
- Chinese Americans have the highest rate of nasopharyngeal cancer in the country;
- Native Hawaiians have the second highest mortality due to lung cancer;
- Diabetes affects Chamorros at 5 times the national average; and Infant mortality rates in the U.S. Pacific insular areas are more than double the national average.

It is clear that the face of America is becoming increasingly diverse as its minority populations continue to grow. And, as our minority populations increase, so will complexity of our health situation.

The Health Care Fairness Act lays out a plan to reduce racial and ethnic disparities in health care and health care outcomes. By elevating the Office of Research on Minority Health to create a Center for Health Disparities Research at the National Institutes of Health (NIH), we will significantly increase the support for research on health disparities, improving data collection relating to race and ethnicity and funding major increases in minority medical training and curriculum development. The NIH needs a strong and effective coordinating body to focus research and awareness of the health care needs of all minorities.

There is much room for improvement to the methods of data collection. Within the Asian American and Pacific Islander community, there exists scant local and federal data to document the needs of our communities. It is only with the emergence of more recent and improved data collection are we beginning to realize the needs of our AAPI communities. This lack of data is our greatest impediment to addressing health disparities. We support the provision to comprehensively study and conduct data collection methods that accurately report the health care status of our communities. I also ask that the National Academy of Science ensure that data collected for Pacific Islanders be disaggregated as directed in the Office of Management



and Budget Policy Directive 15, which was revised in October 1997 and created a new category for "Native Hawaiian or Other Pacific Islander."

The Health Care Fairness Act represents a comprehensive, bipartisan effort to effectively address the health care needs of all our communities. As Chairman of the Congressional Asian Pacific Caucus, I strongly urge your support and commitment to bridge the gap which denies minority Americans from receiving fair access to health care and other quality of life services. I join with my colleagues on this panel to urge you to move this bill forward.

For many years, we have fought this battle in the matter of education. We have acknowledged that there is a strong necessity to address the educational needs of minority communities to level the playing field for all Americans. Now is time to level the playing field so that all Americans, have fair and equal access to health care and health outcomes. I urge you're your strengthened commitment to support comprehensive strategies like the Health Care Fairness Act to address health disparities among ethnic and minority groups. I urge the Committee move this bill forward to markup and passage before we adjourn the 106th Congress.

The Committee's record in addressing the health needs of all minority communities is to be commended. I would like to thank the Committee for its continuing support. I appreciate the opportunity to testify and will remain for any questions.

Mr. COBURN. Mr. Rodriguez?

**STATEMENT OF HON. CIRO D. RODRIGUEZ, A  
REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS**

Mr. RODRIGUEZ. Thank you, Mr. Chairman.

I want to also thank Mr. Bennie Thompson, Congressman Lewis, Congressman Jackson and Congressman Underwood for their efforts in the area of health care.

Let me say the Hispanic Caucus, as of last year, had some hearings and one of the things we found was that there was five areas of concern that we had. One of those was access to health care. As you have indicated, Mr. Chairman, it is not only minorities in that areas, one of the things we found was there is a disparity in terms of Hispanics, that one are one of the largest uninsured groups but beyond that, anyone who is working for a small company, who is not working for government, not working for a major corporation but is making money, doesn't qualify for Medicaid, finds themselves without access to health care. The need for us to do something in that area is key.

Second, we found that the area of funding, when it comes to Hispanics, there is definitely a disparity. We find a lot of community organizations do not have access to those services and there is a need for us to be more responsive in terms of our governmental entities in reaching out.

Third, we found that cultural competency information is key. I will give you an example of when a doctor testified to the fact that we had a woman who was told she was positive when it came to HIV and in Espanol when you say "positivo," it is like in English, you think everything is okay and that is what she thought. Later she had a child and found both were HIV positive. That was unfortunate.

We also found that there is a lack of representation in terms of the health profession in terms of Hispanics in all fields of the health profession. The need for us to make sure that we hold not only agencies accountable but the schools to allow individuals to be able to have that opportunity, to meet some of the needs of our constituents out there.



We found there was a lack of data collection and the need for us to be able to get some data, for example, in finding out why it is that Hispanics are disproportionately hit with diabetes and a variety of other issues.

Those are the five areas we found were critical. This bill allows us an opportunity to move forward in some of those areas and we are optimistic. We are pleased that you are having this hearing to allow us the opportunity to be able to do that.

There is no doubt that there is a need for us to zero in on these areas and make to make sure that we prioritize those items. The individuals you see before you are eager to move forward.

Thank you for allowing us this opportunity.

[The prepared statement of Ciro D. Rodriguez follows:]

PREPARED STATEMENT OF HON. CIRO D. RODRIGUEZ, A REPRESENTATIVE IN  
CONGRESS FROM THE STATE OF TEXAS

Good morning and thank you for the invitation to testify before the Commerce Subcommittee on Health. It is an honor to be here with my colleagues to testify on the health needs of our communities. As representatives of districts with diverse needs we welcome the opportunity to join you in efforts to improve not only the health status of our communities but also of all Americans.

THE CONGRESSIONAL HISPANIC CAUCUS

I currently chair the Congressional Hispanic Caucus Health Task Force. As you may know, the CHC is an informal group of 18 Hispanic Members of Congress dedicated to voicing and advancing issues affecting Hispanic Americans in the United States and the insular areas. We have nine task forces which tackle issues ranging from immigration to economic development. It is primarily out of the CHC's Health Task Force that we work to address health concerns affecting the Latino community.

As Members of Congress, it is our individual responsibility to educate our colleagues about issues of importance to each of the districts we represent. As Members of the CHC, this responsibility increases since we speak for the needs and interests of many more people than those living in the 18 districts we represent. To achieve our collective goals of educating our colleagues and promoting legislation, we compile a list of budget and legislative priorities each year. These priorities serve as a guideline for our colleagues to inform them on issues of importance to their own constituents.

The CHC health agenda is aimed at meeting the needs of our growing and diverse community. There are nearly 30 million Hispanics currently in the United States, constituting approximately 11% of the entire population. By the year 2025 our numbers are expected to increase to nearly 20% of the U.S. population, making Hispanics the largest minority group in the country. The origins of our current population varies: approximately 64%, are Mexican, 14% Central or South American, 11% Puerto Rican, 4% Cuban, and the remaining are from mixed origins. Within these sub-populations we find unique health needs that vary from community to community and neighborhood to neighborhood.

During this 106th Congress, the CHC as a caucus has followed numerous issues related to health care. We worked on issues that range from the clarification of immigrants' ability to enroll in programs such as the Children's Health Insurance Program (CHIP) and Medicaid without jeopardizing their immigration status to participation in events to highlight cultural and ethnic issues related to the delivery of mental health services. Some of the legislative initiatives sponsored by CHC Members include proposals to make health care available to legal immigrants, increase health care access in minority neighborhoods, and improve generally the quality of patient care and rights.

HEALTH DISPARITIES AND THE HISPANIC COMMUNITY

Addressing health disparities is a priority for the Hispanic Caucus. In September 1999, our caucus sponsored Hispanic Health Awareness Week here on Capitol Hill. This effort included a series of hearings sponsored by the CHC on Hispanic health disparities that focused on three areas: diabetes, HIV/AIDS, and mental health. The



purpose of the hearings was to gather information from the community and educate our colleagues here on Capitol Hill about the unique health needs of Latinos.

Although the hearings focused on the impact of specific diseases and highlighted ways to deal with these particular problems, they also provided a broader view of the challenges that we must meet to effectively address the health care needs of Hispanic Americans and all communities of color. These challenges include:

- *Access to Health Care.* Hispanics constitute  $\frac{1}{3}$  of the uninsured population in the United States, which results in large numbers of patients being forced to delay or avoid health care until the problem becomes particularly acute or an emergency.
- *Funding.* Community based organizations that serve the Latino community require additional resources to strengthen existing programs and develop new initiatives.
- *Culturally Competent Information.* Culturally inappropriate, difficult to understand and monolingual, health related information prohibits Latinos from making educated decisions about their well-being and health care options.
- *Representation of Latino Health-Care Professionals.* Latinos are under-represented in the health professions, which increases the barriers related to culturally competent education programs, messages and health care delivery.
- *Data Collection.* Data collected at state and federal levels must be adapted and improved to reflect the needs of the growing and diverse Hispanic population.

The findings compiled from our hearings present a grim reality of the health status of the Latino community. Some of the alarming examples of these problems are:

- type 2 diabetes impacts Latinos at a rate approximately twice that of the non-Hispanic population;
- retinopathy, a debilitating eye disease and a leading complication of diabetes, is 80% higher among Mexican-Americans than among non-Hispanic whites;
- 20% of new AIDS cases occur among Hispanics,
- in 1997, AIDS was the third leading cause of death among Hispanics between 25 and 44; and
- Hispanic girls lead the nation in the rates of suicide attempts, alcohol and drug abuse.

These findings are specific to the Hispanic community but the disparity exists in all communities of color whether it is diabetes, HIV/AIDS, cancer, or mental health. We share the common bonds of despair, fear, and hope that in working together we will not reduce health disparities but rather eliminate them within our lifetime.

The CHC has compiled the information from our hearings into a report that has been officially released. Although we have provided a short summary of the findings and recommendations outlined in our report, we respectfully submit a copy of this report for the committee's review.

#### THE HEALTH CARE FAIRNESS ACT—ADDRESSING HEALTH DISPARITIES

The recommendations presented during our hearings offer options to improve the health care status of Latinos and all Americans. These recommendations included funding for existing programs, genetic research studies to establish why Hispanics are more prone to developing Type 2 diabetes, and adequate representation of Hispanic health care professionals through culturally competent medical and health profession education. Many of the issues raised during the hearings would be addressed through the implementation of H.R. 3250, the Health Care Fairness Act, specifically through the research, data collection and the proper education of our health professionals.

#### Research

The research component to addressing health disparities plays a critical role for our communities. For example, I mentioned before that Hispanics suffer disproportionately from diabetes and in particular Type 2 diabetes. Type 2 diabetes accounts for 90 to 95 percent of diabetes cases nationwide, and it is the most common form in the Hispanic community. With these statistics on just one disease, many wonder why Hispanics are more prone to acquire diabetes.

The proposal within this legislation to establish the National Center for Research on Minority Health and Health Disparities at the National Institutes of Health would address this and many other questions, by working with biomedical institutions, community based agencies, and nonprofit entities that target all minority communities in the United States. Through the Center, we would be able to establish consistent federal support for issues that affect Hispanics and other communities, as well as hopefully include Hispanics in the medical and health services research. Creating this research pipeline for Hispanics and other minorities is key to



ensuring that the health care needs of all minorities will always be on the radar screen at places like the NIH.

These two components go hand in hand in addressing health disparities. If we are to research the specific health needs of minorities communities we must provide opportunities for minorities to be included in the process every step of the way. This includes creating the research pipeline for Hispanics and others of color to become intimately involved in the research process. Along with the loan forgiveness in this section of the legislation, we would advocate aggressive recruitment of all minorities that are under-represented in biomedical research fields. It is our hope that through this legislation, the Center would be able to play a leadership role in increasing NIH's focus on domestic health disparities that have long been ignored.

#### *Data Collection*

Knowing where the health problems are within all of our communities is one of the greatest challenges we face in addressing health disparities. The lack of specific and accurate data on the health and medical needs of Hispanics is particularly challenging given our great diversity. Currently, most data is collected and segregated using Hispanic or Latino without any subdivisions. For example, Mexican Americans may be more prone to diabetes while Cubans may not. Central and South Americans may be more prone to cardiovascular diseases but Puerto Ricans may not. This information is not necessarily available because not all current systems collect along sub-population lines. Accurate data collection with sub-divisions will allow us to target precious resources to the communities in need while at the same time predicting health outcomes.

The issue of data collection is a challenge acknowledged by the Department of Health and Human Services. The Healthy People program has worked to address data collection short falls by establishing critical baseline numbers on more than just the Hispanic community and various subpopulations. However, improved collection and use of standardized data to identify all high risk populations and monitor progress will be needed if we are to make any true strides in eliminating health disparities.

The study proposed in the legislation will allow us to move forward with HHS on furthering data collection efforts and will provide Congress with recommendations on what more can be done. With this study we hope to provide the necessary evidence on the need for strengthened data collection efforts and eventually provide targeted resources to HHS to achieve this goal.

#### *Cultural Competency*

An overwhelming barrier to accessing health care especially for the Hispanic community has been the ability of health professionals to adequately communicate with patients. During the Hispanic Health Awareness hearing, Dr. Barbara Naranjo told a story of a woman in South Texas who was told by a health clinic doctor that her HIV test was positive, or as it was told in Spanish "positivo." No further explanation was given to the woman about what positive or "positivo" meant, therefore she went on with her life, without treatment and critical services. Nearly a year later, Dr. Naranjo was visited by the woman who by that time was pregnant. When an HIV test was done and found to be positive, Dr. Naranjo spoke to the woman about the disease and what it meant. The woman had no idea that she was diagnosed with a life threatening disease that could be transferred to her baby. Nine months later, the baby was born with HIV, something that could have been avoided if the mother had had the disease properly explained to her along with the options in treatment she could receive.

No matter how heart breaking this story is, it is not uncommon. Millions of individuals who lack the basic understanding of medical "lingo" are unable to make informed decisions on what is the best treatment for their diagnosis. Many of these barriers in communication may be eliminated by increasing awareness through cultural competence training for all health professionals and increasing the presence of minorities in all the health profession fields.

Providing cultural competence training in health professionals education curriculum is urgently needed, especially given the tremendous diversity in our population here in the United States. By educating our health professionals on how to deal with the various traditions and cultures within our communities we can be assured that services will be more accessible and effective in reaching communities in need.

Hispanics in general are less likely to seek services because they lack health insurance. Hispanics are also less likely because of the difficulties in navigating the health care system. For instance, hospitals or clinics commonly do not have health professionals that can only speak English. In some cases hospitals have been known



to bring in janitors or other support staff to translate to a patient but not necessarily communicate. All too often we mistake translation for effective communication and this is especially true in the health field. Just because we have spoken to a patient in Spanish or given them a translated document, does not necessarily mean they understand better. Time, patience, and skills acquired from quality cultural competence training must be used in communicating with patients.

Effective and structured curriculum on cultural competence, as suggested within H.R. 3250, would resolve many of the obstacles our communities face on a day to day basis. To further help many of those in the Hispanic community, I would hope we could embrace innovative curriculae that deal with the complex needs of communities of color.

#### CONCLUSION

All of the areas I have focused on are aimed at addressing the health disparities within our communities, and more importantly, in improving access to quality health care. Hispanics are the largest uninsured minority population at nearly 40% without health insurance. I ask that this Committee take into consideration the health needs of millions of Americans as we work on the health disparities within our communities.

For far too long we have failed to truly address the needs of communities disproportionately suffering from health disparities. H.R. 3250 is the first step we must all take in finally addressing the health care needs of a large segment of our population. If we fail to act on this legislation we fail far too many people. Do not forget that these individuals are not faceless or nameless. They are the people we have been elected to represent. Let us do our job and work to pass this legislation.

I applaud the efforts of this Committee to address minority health and the needs of the Hispanic community. I look forward to working with you and ask that you use the Hispanic Caucus as a resource for any future legislation the Committee may consider. I appreciate the opportunity to testify and will remain for questions from members of this Committee.

Mr. COBURN. The gentleman from Arizona, Mr. Hayworth.

#### **STATEMENT OF HON. J.D. HAYWORTH, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ARIZONA**

Mr. HAYWORTH. Thank you. It is a honor to be here with you.

I am here today in my capacity as co-chairman of the Congressional Native American Caucus. I want to thank you, Mr. Chairman, for offering all of us this opportunity to testify on H.R. 3250, the Health Care Fairness Act. I would like to commend all of you for holding this hearing on ways to address minority health disparities and health research education and access to health care in minority populations.

In 1976, Congress enacted the Indian Health Care Improvement Act. The Act is one of the most comprehensive efforts by Congress to address the health needs and health status of American Indian and Alaska Natives. Although improvements in the health status of American Indians and Alaska Natives have been accomplished, the unmet health needs of this population continue to be staggering.

As indicated in recent studies by the Centers for Disease Control and Prevention, the disparity between the health of Native Americans and the rest of the population is ever widening. Native Americans suffer the worse health status of any racial or ethnic group in America with a diabetes rate that is three times greater than the general population and a death rate 4.3 times greater than the general population from complications of diabetes.

In addition, Native Americans suffer rates of heart disease two times as high as the general population. Cancer and alcoholism are six times the national rate. Hepatitis is two times as high as the



general population and tuberculosis at five times the rate of the general population.

A stunning example of the disparity is the Gila River Indian Community in the 6th Congressional District of Arizona whom I represent. The community is well known to medical officials for its shockingly high rate of Type II adult onset diabetes. According to the World Health Organization, the Pima Indians who make up the majority of this community's population, have the highest known rate of diabetes in the world. Community members are 12 times more likely to die of diabetes and its severe complications than the average American.

For over three decades, members of the community have been studied by the National Institutes of Health and outside parties. The National Institute for Diabetes and Digestive and Kidney Diseases has supported a field research station in Arizona since 1965. Community members have been weighed, poked, prodded, x-rayed and screened at a cost to taxpayers more than \$100 million.

Based on the data obtained, NIH was able to develop new approaches to the treatment of Type I diabetes, juvenile diabetes. The NIH research program findings failed to study the treatment prevention of Type II diabetes, the type of diabetes that affects the very people who were used to obtain the data.

Despite three decades of research, the Type II diabetes epidemic within the community continues to accelerate. In a disturbing development, the age of onset of Type II diabetes has been decreasing steadily. In fact, within the community, the term adult onset diabetes is rapidly becoming a misnomer. The community also has the largest known cluster of children with Type II diabetes in the world.

Congress has a special trust responsibility to assure the highest possible health status is achieved for Native Americans. Despite the trust responsibility, Native Americans and Alaskan Natives continue to bear a disproportionate burden of illness and premature mortality in comparison with other American populations.

The lesson to learn from the Gila experience is that tribal self interests must be taken into consideration. Congress must look for ways to give tribes more direct control over the prevention, intervention and treatment of serious diseases affecting their populations.

We look forward to working with the committee to develop solutions for innovative and culturally sensitive methods to address health disparities for Native Americans and Alaska Natives.

Again, I thank the Chair and the committee.

[The prepared statement of Hon. J.D. Hayworth follows:]

PREPARED STATEMENT OF HON. J.D. HAYWORTH, A REPRESENTATIVE IN CONGRESS  
FROM THE STATE OF ARIZONA ON BEHALF OF HIMSELF AND HON. DALE E. KILDEE

Mr. Chairman, good morning. As Co-chairman of the Congressional Native American Caucus, I want to thank you for giving me this opportunity to testify on H.R. 3250, the Health Care Fairness Act. I commend the Chairman and other distinguished committee members for holding a hearing today on ways to address minority health disparities in health research, education, and access to health care in minority populations.

In 1976, Congress enacted the Indian Health Care Improvement Act. The Act is one of the most comprehensive efforts by Congress to address the health needs and health status of American Indian and Alaska Natives. Although improvements in



the health status of American Indians and Alaska Natives have been accomplished, the unmet health needs of this population continue to be staggering.

As indicated in the recent studies by the Centers for Disease Control and Prevention (CDC), the disparity between the health of Native Americans and the rest of the population is ever-widening. Native Americans suffer the worst health status of any *racial or ethnic group* in America with a diabetes rate that is 3 times greater than the general population, and a death rate 4.3 times greater than the general population from complications of diabetes. In addition, Native Americans suffer rates of heart disease 2 times as high as the general population, cancer and alcoholism 6 times the U.S. rate, hepatitis 2 times as high as the general population, and tuberculosis at 5 times as high as the general population.

A stunning example of this disparity is the Gila River Indian Community in Arizona. The Community is well-known in the medical community for its shockingly high rate of Type 2 (adult-onset) diabetes. According to the World Health Organization, the Pima Indians, who make up the majority of the Community population, have the *highest known rate of diabetes in the world*. Community members are twelve times more, likely to die of diabetes and its severe complications than the average American.

For over three decades, members of the Community have been studied by the National Institutes of Health (NIH) and outside parties. The National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK) has supported a field research station in Arizona since 1965. Community members have been weighed, poked, prodded, x-rayed, and screened at a cost to taxpayers of more than \$100 million.

Based on the data obtained, NIH was able to develop new approaches to the treatment of Type 1 diabetes, juvenile diabetes. The NIH research program findings failed to study the treatment and prevention of Type 2 diabetes, the type of diabetes that affects the very people who were used to obtain the data. Despite three decades of research, the Type 2 diabetes epidemic within the Community continues to accelerate.

In a disturbing development, the age of onset of Type 2 diabetes has been decreasing steadily. In fact, within the Community the term "adult-onset" diabetes is rapidly becoming a misnomer; the Community also has the largest known cluster of children with Type 2 diabetes in the world.

Congress has a special trust responsibility to assure the highest possible health status for Native Americans. Despite the trust responsibility, American Natives and Alaska Natives continue to bear a disproportionate burden of illness and premature mortality in comparison with other U.S. populations. The lesson to learn from the Gila experience is that tribal self-interest must be taken into consideration. Congress must look for ways to give tribes more direct control over the prevention, intervention, and treatment of, serious diseases affecting their population.

We look forward to working with the committee to develop solutions for innovative and culturally-sensitive methods to address health disparities in Native Americans and Alaska Natives.

Mr. COBURN. Mr. Watts.

**STATEMENT OF HON. J.C. WATTS, A REPRESENTATIVE IN  
CONGRESS FROM THE STATE OF OKLAHOMA**

Mr. WATTS. Thank you very much for holding this hearing.

I am going to have to leave shortly after my testimony so I do appreciate you being with me.

I would again like to thank you for holding this hearing today concerning H.R. 3250, the Health Care Fairness Act. I would also thank my colleagues who are present today, especially Mr. Lewis, Mr. Norwood and Mr. Jackson and all the other members who have championed this critical legislation.

I am also proud testifying here today is Mr. John Harley, a member of the Oklahoma Medical Research Foundation. OMRF is truly a beacon of excellence in scientific research for the State of Oklahoma and the Nation. The scientists at OMRF play a significant role in uncovering clues to the origin of human disease and thereby building a biomedical industry. OMRF discoveries are helping to lead the way in the fight against cancer, heart disease, stroke, dia-



betes, lupus and other diseases that plague mankind, and especially minorities.

Just as biomedical research is helping to address the disparities in health, so will the Health Care Fairness Act. The Act comprehensively addresses health disparities by elevating the existing Office of Research on Minority Health at the National Institutes of Health to a National Center for Research on Minority Health. It also addresses bias in health care through education and an improved data system, and strengthened public awareness.

Despite continued advances in research and medicine, disparities in health care are an ever increasing problem and a concern. This is evidenced by the fact that minority Americans lag behind on nearly every health indicator including health care coverage, access to care, life expectancy and disease rates.

Ethnic minorities and individuals in medically underserved rural communities continue to suffer disproportionately from many diseases such as cancer, diabetes and cardiovascular diseases.

There have been numerous studies in scientific journals showing the severity of racial and ethnic health disparities and the need for action in order to remedy this grave problem. As previously noted, disease rates and access to health care are two of the many different facets of disparity.

In October 1999, the Henry J. Kaiser Family Foundation found that many studies have repeatedly documented that African-Americans were significantly less likely than whites to receive diagnostic and surgical interventions for heart disease and stroke. Numerous studies have also found that racial and ethnic minorities were more likely than whites to be diagnosed with cancer at advanced stages and less likely to receive major therapeutic intervention.

With regard to diabetes to which I lost a mother several years ago, racial differences have been documented and the degree and method of diabetes control.

In closing, I would like to point out the obvious. Access to quality health care is crucial. We must all work together to see that the health care needs of everyone, including minorities in rural populations, are met. There is no single cause of racial disparities in health and there is no single solution but there is no doubt that greater public awareness is mandatory if we are going to have an impact on this problem.

Elimination of health disparities must be a higher priority. The Health Care Fairness Act will increase our knowledge of the nature and causes of health disparities, improve the quality and outcomes of health care services for minority populations and aid in bringing us closer to our mutual goal of closing the longstanding gap in health care.

I am deeply committed to this piece of legislation and I urge all Members of Congress to support us in our effort to rectify this inequality in health care.

Mr. Chairman, Mr Coburn, and members of the committee, I thank you for your time and your sincere interest in addressing this critical issue.

Mr. COBURN. Thank you.

I believe the committee is not going to be asking questions of this panel. I do want to tell you that I think all members of the sub-



committee see the problem is real and we will be making every effort to support you in your efforts.

Mr. BILIRAKIS. Certainly, the details of the larger bill, Mr. Lewis' and Mr. Thompson's bill, are significant, however, the Center might be a stumbling block. We would hope it would not be.

I wanted to suggest to you knowing that—and Mr. Jackson and I have had long discussions about this—you may want to gather together your ammunition to address the things Mr. Jackson and I spoke about. Some of us feel very strongly about creating the Center and there are others who raise technicalities, the fact that the director apparently—maybe we will find out more in a little while—is not supportive or at least is not expressing any support.

Thank you.

Not knowing whether Mr. Coburn has placed into the record the opening statements of all members of the subcommittee, I will now say that without objection, all opening statements are made a part of the record.

First, I do want to apologize. I had a Veterans Committee markup on an education bill for veterans and that was scheduled for 10 a.m., so we scheduled this hearing for 11:30 a.m., figuring I would be able to get out of that. Then they called the votes shortly after 10 a.m. and we had six votes which meant that markup was delayed, consequently everything was set back for me. I appreciate Mr. Coburn taking the time to come over and get things started so we did not get started too late.

Panel two will consist of the Honorable David Satcher, U.S. Surgeon General, accompanied by Mr. Kermit Smith, Chief Medical Officer, Indian Health Service and Mr. John Ruffin, Associate Director, Research on Minority Health, National Institute of Health. Thank you gentlemen. Welcome to our hearing.

Mr. Satcher, you are testifying on behalf of the Administration. The clock ordinarily is 5 minutes. You have 10 minutes and hopefully you can get your point across within that period of time but we will extend it if we have to.

Please proceed, sir.

**STATEMENT OF HON. DAVID SATCHER, U.S. SURGEON  
GENERAL, DEPARTMENT OF HEALTH AND HUMAN SERVICES**

Mr. SATCHER. Thank you very much. I want to express my appreciation for the invitation to testify at this very important hearing on ways to improve the quality of health and health care for minorities and H.R. 3250, the Health Care Fairness Act of 1999.

As you pointed out, with me today are experts from the Indian Health Service, Dr. Kermit Smith, and Dr. John Ruffin, the Associate Director of the Office of Research on Minority Health at NIH.

Let me say how much we appreciate the testimony of Panel I and the presence of Secretary Sullivan and his outstanding contributions in this area before, during and since he served as Secretary of the Department of Health and Human Services.

I also want to acknowledge Jordan Cohen from the Association of Medical Colleges who in the face of incredible odds has worked so hard to improve the representation of minorities in the health profession.



Your topic could not be more appropriate as we examine the state of minority health in America. We are really addressing the status of our Nation's health overall and the strength of our public health system.

Despite notable progress in overall health of the Nation, there are continuing disparities in the burden of illness and death experienced by African-Americans, Hispanics, American Indian and Alaska Natives and Pacific Islanders compared to the U.S. population as a whole. These disparities are not explained by biologic or genetic characteristics of racial and ethnic groups. Instead, they are believed to be the results of a complex interaction among genetic variation, environmental factors, economics, specific health behaviors and discrimination in access and quality of health care.

The Department of Health and Human Services adopted the commitment to eliminate disparities in health on the basis of race and ethnicity by the year 2010. I think we did this first in response to President Clinton's request that a health component be added to the Race Initiative which he announced in 1997.

Second, the goal of eliminating disparities in health is one of the two goals of Healthy People 2010. We will focus initially on six key areas that reflect areas of disparity across multiple racial and ethnic minority groups. They are infant mortality, breast and cervical cancer screening and management, cardiovascular disease risk factor reduction, diabetes complications, adult and childhood immunizations and HIV infections and AIDS.

We want to make it clear, however, that we are not limiting our efforts to these six areas with which we will begin. There are many other areas of disparity. Sunday, we will celebrate Mother's Day. Earlier this morning, I was with Congresswomen Nita Lowey and Cynthia McKinney to talk about safe motherhood. African-American women are four times more likely to die during and around pregnancy than the majority of women in this country.

We could talk about asthma. There are several areas of disparity and the idea here is to begin with these six where we have the kind of data base that we can measure our progress and we believe we can have a great impact. All of these areas are of concern to us.

I want to speak briefly about what we are doing since you have heard the statistics relative to these disparities. We have begun a program to address disparities starting with President Clinton's announcement in February 1998 shortly after I became Surgeon General. One component of the Department's initiative is the Racial and Ethnic Approaches to Community Health, REACH-2010. It is designed to help communities mobilize and organize their resources in support of effective and sustainable programs that will eliminate health disparities.

So far, 32 communities have been funded to develop plans for eliminating disparities in 1 of these 6 areas, some of them more than one. The communities with acceptable plans will receive programmatic funding during Phase II and new communities will be funded later this year.

The Office of Civil Rights has played a very critical role in the Department's initiative to eliminate disparities in health. They have focused on enforcement, education and outreach and I think



are doing a great job. I want to give you a few examples of the work of the Office of Civil Rights. These cases illustrate the discrimination that regrettably still is alive and well in the health care setting.

The Office of Civil Rights recently reached a settlement with the National Home Health Agency that had engaged in medical redlining, that is, it refused to serve a predominantly minority area of New Haven, Connecticut. The Office of Civil Rights reached an agreement with a national pharmacy chain that had repeatedly failed to fill prescriptions of an African-American Medicaid recipient in Texas. The Office of Civil Rights reached a settlement with a hospital in South Carolina that had a policy in effect of not giving epidurals to women who did not speak English.

There were several of these kinds of experiences but I think we are finding that through a process of enforcement, education and communication, that we can, in fact, make significant progress.

The NIH has established a Working Group on Health Disparities that is currently developing a strategic plan to expand training programs for minority researchers to set priorities and to synchronize multidisciplinary research. That strategic plan will be reviewed by the Office of Research on Minority Health and its Public Advisory Committee.

I do want to point out that after much discussion, the former Director of NIH, Dr. Varmus, has written a letter in support of the development of the Center and certainly the present Acting Director of NIH, Dr. Ruth Kirschstein supports the development of the Center. I wanted to make that point because I think it is important as you pointed out in terms of their positions.

Addressing the challenge of health improvement is a shared responsibility that requires the active participation and leadership of the Federal Government, State and local government, other policymakers, health care providers, professionals, business leaders, et cetera. The Agency for Health Care Research and Quality plans to establish four centers of excellence this summer that will identify practical tools and strategies to eliminate racial and ethnic disparities in the health care system. HRSA is leading a campaign for 100 percent access and zero percent disparities by the year 2010.

An area of development that I think is really important is the development of partnerships between our department and many private sector groups. We are partnered with Grantmakers in Health which represents over 200 health-related foundations in this country. They are working with foundations and corporate giving programs to improve the Nation's health. They have made elimination of disparities a priority.

The California Endowment has initiated a program in multicultural health aimed at eliminating health disparities and through collaboration with the CDC Foundation, has already funded three additional Reach 2010 projects in California.

Likewise, the Robert Wood Johnson Foundation, the Commonwealth Foundation, the Kaiser Family Foundation and others have funded programs for the elimination of disparities in health.

On April 24, 2000, our department and the American Public Health Association announced a partnership to eliminate racial and ethnic disparities. The partnership includes a three phase plan



to develop a charge or blueprint of guidelines for our collaboration, develop a detailed comprehensive national plan, and third, to implement that plan by 2002.

It is important to note the American Public Health Association represents 55,000 members, many of them leaders in public health throughout this country. When asked to rank issues for the year 2010, they listed elimination of disparities as their No. 1 priority. We are happy to be partnering with the American Public Health Association.

The role of the Health Care Fairness Act of 1999 in improving minority health is significant, and I will close with these comments.

We thank you for your support of our initiative to eliminate racial and ethnic disparities in health and its parallel emphasis with Healthy People 2010. The proposed Health Care Fairness Act of 1999 addresses several key elements the department has identified as essential to a comprehensive approach toward eliminating disparities. They include the development of a balanced and comprehensive research agenda that addresses the unequal burden of morbidity and mortality in racial and ethnic minorities.

Supporting efforts to improve the quality and outcome of health care services as well as addressing the social determinants of health including but not limited to access to care, the ten leading health indicators of Healthy People 2010, five of which deal with lifestyle and five with health care system issues; strengthening the data collection infrastructure of HHS; recognition of the important role of the Office of Civil Rights; and support for graduate health education curriculum development and continuing medical education efforts to reduce disparity in health and health outcomes as well as increasing the knowledge base with respect to cultural competency.

Mr. Chairman and members of the committee, as Surgeon General of the United States and as one who has a major responsibility in this area, I am encouraged by the evidence of the bipartisan, public-private, and Federal, state and local commitment that is developing in this country.

As we continue our work to improve the lives of our fellow Americans, let me leave you with the premise upon which the U.S. Public Health Service was founded in 1798 as the Marine Hospital Service. That premise is, "to the extent that we respond to the needs of the most vulnerable among us, we do most to promote and protect the health of the Nation." Thank you for the opportunity to share with you some of our department's activities and our perspectives. We appreciate your support and we look forward to our continuing partnership to improve health and the health care system in this country.

We would be happy to respond to any questions.

[The prepared statement of Hon. David Satcher follows:]

PREPARED STATEMENT OF DAVID SATCHER, ASSISTANT SECRETARY FOR HEALTH AND SURGEON GENERAL, U.S. PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Good morning. I am David Satcher, Assistant Secretary for Health, Department of Health and Human Services (HHS), and Surgeon General of the United States. I thank you, Mr. Chairman and members of the Committee, for your invitation to



testify at this important hearing on how to improve the quality of health care for minorities and H.R. 3250, The Health Care Fairness Act of 1999. With me today are technical experts from the HHS agencies involved in ensuring the quality of health care for all Americans. They are: Kermit C. Smith, D.O., the Chief Medical Officer of the Indian Health Service; and John Ruffin, Ph.D., Associate Director Office of Research on Minority Health at the National Institutes of Health.

Let me say that the topic of your hearing could not be more appropriate, for indeed, as we look at the state of minority health in America we are really looking into the future of our nation's health.

#### BACKGROUND ON MINORITY HEALTH

In the 1985 Report of the Secretary's Task Force on Black and Minority Health, Secretary Margaret M. Heckler wrote these words, "In January 1984—ten months after becoming Secretary of Health and Human Services—I sent *Health, United States, 1983* to the Congress. It was the annual report of the health status of the American people. That report—like its predecessors—documented significant progress: Americans were living longer, infant mortality had continued to decline—the *overall* American health picture showed almost uniform improvement. But, and that "but" signaled a sad and significant fact, *there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nation's population as a whole*. That disparity has existed ever since accurate federal record keeping began—more than a generation ago. And although our health charts do itemize steady gains in the health of minority Americans, the stubborn disparity remained—an affront both to our ideals and to the ongoing genius of American medicine. The report is comprehensive. Its analysis is thoughtful. Its thrust is masterful. It sets the framework for meeting the challenge—for improving the health of minorities. It can—it should—mark the beginning of the end of the health disparity that has, for so long, cast a shadow on the otherwise splendid American track record of ever improving health."

It is now the year 2000.

Compelling evidence that race and ethnicity correlate with persistent, and often increasing, health disparities among U.S. populations demands national attention. Indeed, despite notable progress in the overall health of the Nation, there are continuing disparities in the burden of illness and death experienced by African Americans, Hispanics, American Indians, Alaska Natives, and Asian Pacific Islanders, compared to the U.S. population as a whole. Current information about the biologic and genetic characteristics of racial and ethnic groups does not explain the health disparities experienced by these groups compared with the white, non-Hispanic population in the United States. These disparities are believed to be the result of the complex interaction between genetic variations, environmental factors, economics, specific health behaviors, and discrimination.

Even though the Nation's infant mortality rate is down, the infant mortality rate among African Americans is still more than double that of white citizens. Heart disease death rates are more than 40 percent higher for African Americans than for whites. The death rate for all cancers is 30 percent higher for African Americans than for whites; for prostate cancer, it is more than double that for whites. African American women have a higher death rate from breast cancer despite having a mammography screening rate that is higher than for white women. The death rate from HIV/AIDS for African Americans is more than seven times that for whites; the rate of homicide is six times that for whites.

Hispanics living in the United States are almost twice as likely to die from diabetes as are non-Hispanic whites. Although constituting only 11 percent of the total population in 1996, Hispanics accounted for 20 percent of the new cases of tuberculosis, and have higher rates of hypertension and obesity than non-Hispanic whites. There are differences among Hispanic populations as well. For example, whereas the rate of low-birth-weight infants is lower for the total Hispanic population compared to whites, Puerto Ricans have a low-birth-weight rate that is 50 percent higher than that for whites.

American Indians and Alaska Natives have an infant mortality rate almost double that of whites. The rate of diabetes for this population group is more than twice that for whites. The Pima of Arizona have one of the highest rates of diabetes in the world. American Indians living in North and South Dakota have an average life expectancy that is 11 years less than that for the rest of the U.S. population. Overall, the life expectancy for American Indians and Alaska Native is 71 years of age—nearly five years less than the U.S. Races populations.

Asian and Pacific Islanders, on average, have indicators of being one of the healthiest population groups in the United States. However, there is great diversity



within this population group, and health disparities for some specific groups are quite marked. Vietnamese women suffer from cervical cancer at nearly five times the rate of white women. New cases of hepatitis and tuberculosis are also higher in Asians and Pacific Islanders living in the United States than in whites.

The Indian Health Service (IHS) and Native American Tribes have made much progress improving the American Indian and Alaska Native health status over the years. Infant mortality rates, maternal death rates, morbidity and mortality from infectious diseases have all decreased dramatically over the past 40 years. However, during the last five years, this progress has stalled and indeed regressing in some areas. American Indian infant mortality is beginning to increase in some communities. During 1992-1994, the infant mortality rate for the IHS Phoenix Regional Area was 9.4 deaths per 1,000 live births. The rate increased to 9.7 from 1994-1996. In the IHS Nashville Regional Area, the rate increased from 11.6 per 1,000 live births to 11.7 over the same time frame.

Behavior-related mortality rates for the American Indian population residing in the IHS regional service areas are rising. For example, age-adjusted mortality rates for AI/ANs due to alcoholism, suicide, and homicide during 1992-1994 were 45.5, 19.2, and 15.1 deaths per 100,000 persons, respectively. The 1994-96 data indicate these numbers increased to 48.7 deaths per 100,000 for alcoholism, 19.3 for suicide, and 15.3 for homicide. During this time period, the age-adjusted mortality rate for AI/AN for HIV infections rose 59 percent, and for diabetes mortality, an increase of 13 percent. Increases in age-adjusted mortality rates are also noted for this population in malignant neoplasms and cerebrovascular disease.

Slight improvement has been made between 1992-1994 and 1994-1996 in age-adjusted mortality rates for AI/ANs due to Tuberculosis (a rate of 2.3 improved to a rate of 1.9) and heart disease (a rate of 157.6 improved to a rate of 156.0). However, increases in age-adjusted mortality rates were experienced for AI/ANs deaths due to malignant neoplasms (a rate of 112.2 during 1992-1994 increased to a rate of 116.6 during 1994-1996) and for AI/ANs deaths due to cerebrovascular diseases (a rate of 27.8 during 1992-1994 increased to a rate of 30.5 during 1994-1996). The bottom line figure of life expectancy at birth for American Indian and Alaska Native population in the IHS regional service delivery areas remained exactly the same between the 3-year period 1992-1994 and 1994-1996, 71 years.

#### HHS INITIATIVE TO ELIMINATE DISPARITIES IN HEALTH

The demographic changes that are anticipated over the next decade magnify the importance of addressing disparities in health status. Groups currently experiencing poorer health status are expected to grow as a proportion of the total U.S. population; therefore, the future health of America as a whole will be influenced substantially by our success in improving the health status of our racial and ethnic minorities.

In June 1997, President Clinton introduced to the country the concept of *One America in the Twenty-first Century: The President's Initiative on Race*. He appointed a national advisory board led by John Hope Franklin, and in their September 1998 report to the President, "One America in the 21st Century: Forging a New Future," they included their observations on what they saw and heard about race and its impact upon communities throughout the country. The Board report also offers recommendations on specific steps that should be taken to eliminate racial disparities experienced by people of color.

Additionally, the President asked each cabinet head to develop some strategy supporting the Race Initiative. In the Department of Health and Human Services, we adopted the commitment to eliminate disparities in health on the basis of race and ethnicity by the year 2010. The President announced this unprecedented initiative from the White House in February 1998. We focus on six key areas: infant mortality, breast and cervical cancer screening and management, cardiovascular disease risk factor reduction, diabetes complications, adult and childhood immunizations, and HIV infections and AIDS. These six health areas were selected for emphasis for they reflect areas of disparity that are known to affect multiple racial and ethnic minority groups at all life stages and are areas over which we could have direct impact.

This Initiative marks the first time in the history of our government that we have made the commitment to eliminate, not just reduce, the health disparities between majority and minority populations. Additionally, the Initiative will parallel the second goal of Healthy People 2010, the Nation's disease prevention, health promotion agenda for the first decade of the 21st century. The other goal is to increase the quality and years of healthy life.



The Initiative is led by the Office of Public Health and Science (OPHS) and the responsibility for overall guidance within HHS is the Public Health Council (PHC).

Beginning shortly after the President's announcement, working groups comprised of experts from the agencies within HHS met to discuss the status of HHS programs and policies in the six health focus areas and the data issues relevant to the Initiative. These working groups have generated full length reports that review the epidemiology of the six focus areas and examine a range of strategies for effective interventions for prevention and treatment. The reports offer recommendations for future research, policies, and program investments that would lead to the elimination of health disparities.

One of the most visible components of the HHS Initiative is the Racial and Ethnic Approaches to Community Health 2010 program (REACH 2010). REACH 2010 is intended to help communities mobilize and organize their resources in support of effective and sustainable programs that will eliminate health disparities. In FY 1999, Congress appropriated \$10 million dollars to the Centers for Disease Control and Prevention (CDC) to administer the program. The first year of REACH demonstrations was designed as a planning year to solidify the multi-agency, community oriented collaboration required of the applicants. Subsequent years will involve implementation of the interventions to address one or more of the six clinical focus areas within a well-defined population.

CDC used this appropriation to fund 32 community coalitions and three additional community coalitions were funded by the California Endowment to participate in REACH 2010. The populations targeted include African-American, American Indian, Alaska Native, Hispanic American, Asian American, and Pacific Islander. Of the awards, five were for infant mortality, five for breast and cervical cancer screening and management, four for immunizations, twelve for diabetes complications prevention, twelve for cardiovascular disease risk factor reduction, and two for HIV infection and AIDS. These awards were spread over 18 states and 22 cities.

The FY 2000 appropriation of \$30 million will be used to implementation of the community derived strategies and to enlist new community coalitions in the effort to eliminate disparities.

The Office of Civil Rights (OCR) has played a critical role in the department's Initiative to Eliminate Racial and Ethnic Disparities. Through enforcement, education and outreach, OCR has raised public awareness of the role of discrimination as one explanatory factor in racial and ethnic disparities. Recent OCR cases illustrate the discrimination regrettably is alive and well in the health care setting.

1. OCR reached a settlement with a national home health agency that had engaged in medical redlining, that is, it refused to serve a predominantly minority area of New Haven, Connecticut;
2. OCR reached an agreement with a national pharmacy chain that had repeatedly failed to fill the prescription of an African-American Medicaid recipient in Texas;
3. OCR reached a settlement with a hospital in South Carolina that had a policy in effect of not giving epidurals to women who did not speak English; and
4. OCR reached a settlement with a hospital in Philadelphia whose lack of an effective policy for treating patients who do not speak English created serious problems for a pregnant woman who needed emergency care.

OCR's enforcement, coupled with recent research documenting the potential role of racial bias in explaining physician decision-making, illustrate that eliminating racial and ethnic disparities is both a civil rights and a public health challenge. If we ignore the former and focus solely on the latter, we will not be fully successful.

Addressing the challenge of health improvement is a shared responsibility that requires the active participation and leadership of the Federal Government, States, local governments, policymakers, health care providers, professionals, business executives, educators, community leaders, and the American public itself.

A national partnership is needed to develop a balanced community health system that promotes healthy lifestyles and behaviors, and in challenges a health care delivery system that allows for unequal outcomes on the basis of race and ethnicity. The task of HHS is to provide leadership through conducting innovative and balanced research, expanding and improving programs to purchase or deliver quality health services, developing programs to reduce poverty and provide children with safe and healthy environment, and by expanding prevention efforts. Currently, our activities include, but are not limited to:

- In October 1997, the Secretary issued the first Federal agency policy requiring the inclusion of racial and ethnic data in all of its data systems, with very few exceptions. The inclusion policy also required compliance with the Federal standards for racial and ethnic data.



- In February 2000, the HHS Data Council's Working Group on Racial and Ethnic Data and the Data Working Group of the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health presented their joint report on "Improving the Collection and Use of Racial and Ethnic Data in HHS" to the Data Council. This report builds upon the numerous recommendations developed in the past and presents a long term agenda for improving the collection and use of racial and ethnic data across the Department and its agencies. This report sets the stage for the National Academy of Sciences report which is called for in the Health Care Fairness Act under discussion today.
- The Health Care Financing Administration (HCFA) now requires each state Peer Review Organization (PRO) to include a focus on eliminating racial and ethnic disparities in health. PROs had previously been required to focus on improving quality of care in several other key clinical areas closely related to the Initiative.
- The Agency for Healthcare Research and Quality (AHRQ) plans over the next five years to establish up to four "centers of excellence" that will identify practical tools and strategies to eliminate racial and ethnic disparities in the health care system. The research conducted by these centers will go beyond documenting disparities by putting a new emphasis on understanding their underlying causes and developing strategies to eliminate them.
- In February 2000, an important working conference, "Diversity and Communication in Health Care: Addressing Race, Ethnicity, Language, and Social Class in Health Care Disparities" was sponsored by the Office of Minority Health, the Health Resources Services Administration (HRSA), AHRQ, the Commonwealth Fund, and the Sergei Zingoff Fund for Medical Education and Research. The purpose of the conference was to determine the state-of-the-art for improving provider-patient communication, to define its adequacy to increase effectiveness of health care for racial and ethnic minorities, and to develop a work plan to provide needed modifications. A larger conference is called for in the Health Care Fairness Act.
- In addition to the work discussed earlier, the Office of Civil Rights is focusing on a program of dialogue and education of health care providers and patients to increase awareness of civil rights responsibilities. For instance, in New York City, OCR has convened a series of meeting with all stakeholders-providers, advocates, faith communities, foundations, medical societies, hospital associations, and others in an effort to develop a greater understanding of the root causes of racial and ethnic disparities, as well as a blueprint for eliminating disparities. This dialogue has been extremely productive, and talk has led to constructive action. At the same time OCR has begun to look at data pertaining to hospitals to determine why some high tech medical procedures do not appear to be performed on minorities at the same rate as non-minorities.
- HRSA has launched a campaign for 100 percent access, 0 percent disparities by the year 2010. As part of its mission to provide quality comprehensive health care to under served and vulnerable populations, HRSA hopes to build and sustain healthier communities by empowering communities to identify and develop solutions tailored to their needs. Currently, 23 states and over 100 communities are engaged in the campaign. Additionally, HRSA has funded 10 communities across the country to address significant disparities in perinatal health indicators. These communities demonstrated significant infant mortality and morbidity rates, had an existing consortia of stakeholders with infant mortality reduction experience, and developed a feasible plan to reduce barriers, improve systems of care, and eliminate disparities.
- As required in the re-authorization of the Office of Minority Health, HHS is establishing its first Advisory Committee on Minority Health. We understand that this advisory committee could serve the role of that called for in the Health Care Fairness Act to provide advice to the Secretary on matters related to the development, implementation, and evaluation of graduate and continuing education curricula for health care professionals to decrease the disparities in health care and health outcomes.
- The National Institutes of Health (NIH) remains committed to conducting research on the diagnosis, treatment, and prevention of diseases resulting in health disparities, including AIDS, cancer, diabetes and heart disease. We recognize that these efforts would be enhanced by a central organization that coordinates and reviews the health disparity research being conducted by the NIH's various Institutes and Centers. Therefore, NIH has established a Working Group on Health Disparities that is currently developing a Strategic Plan to expand training programs for minority researchers, set priorities and synchronize multi-disciplinary research. The Strategic Plan will be reviewed by the



Office for Research on Minority Health and its public Advisory Committee. The unprecedented level of coordination and input from the public, including those most affected by health disparities, and the prominent role played by the Office for Research on Minority Health, should result in measurable improvements.

- The Indian Health Service, Department of Health and Human Services, and the Administration are working with Indian Tribes to address the disparity in health status among American Indian and Alaska Native people. During the past 3 years the Indian Tribes have identified alcoholism/substance abuse, diabetes, cancer, heart disease, infectious disease, maternal and child health, mental health, injuries and domestic/community violence as the top health problems that must be addressed by the IHS budget requests. Local IHS/Tribal/Urban(ITU) health priorities dovetail with the President's Race Initiative on Health Disparity focus and underpin the Indian health budget priorities set by the Indian Tribes and the Administration in the past 2 years.
- The IHS, tribes and urban health programs have demonstrated the ability to improve the health status of American Indian and Alaska Native people. Improving essential access to health care in order to address health disparities has been a top priority for the I/T/U's annual budget and Government Performance and Results Act performance plan initiatives. The first annual performance report, which was submitted for FY 1999, provides a base performance level for the health interventions/measures that will ultimately lead to improved outcomes in health status. Indian Tribes are becoming increasingly involved in developing the performance targets. Joint Federal-Tribal efforts are directed toward achieving these targets as a means of demonstrating the effectiveness of the I/T/U programs to make a difference in the disparities that exists between the health of American Indian/Alaska Native people and the rest of the United States.

#### PUBLIC/PRIVATE PARTNERSHIPS TO IMPROVE MINORITY HEALTH

As the Nation enters a new millennium, an unprecedented opportunity exists to influence and effect health in a way that is fundamentally fair, and more inclusive of all Americans. HHS has "stepped to the plate" to eliminate disparities in health and has created an environment where private foundations and endowments are engaging their colleagues to eliminate disparities in health. For example:

- HHS and Grantmakers in Health (GIH), an educational organization that works with foundations and corporate giving programs to improve the nation's health, cosponsored a national leadership conference in September 1998, to discuss strategies for developing and strengthening partnership focusing on eliminating racial and ethnic disparities in health by 2010. Attending the conference were approximately 250 key public policy makers, industry and community leaders, including individuals representing foundations, community-based organizations, national organizations with expertise in key health areas and with a history of serving racial and ethnic groups, providers, insurance companies and managed care plans, the media, business, faith-based organizations, and consumers.
- The California Endowment has initiated a Program in Multi-cultural health aimed at eliminating health disparities and through collaboration with the CDC Foundation, funded three additional REACH 2010 projects in California.
- The Robert Wood Johnson Foundation's Investigators Award in Health Policy Research Programs is seeking to improve understanding of the social determinants of health.
- The Commonwealth Fund cosponsored a meeting with managed care organizations on data collection, quality of care measurement, and access to health care. As a result, efforts are being made to educate health plans that the Federal government does not prohibit the collection of racial and ethnic data.
- The Henry J. Kaiser Family Foundation hosted a conference on "Race, Ethnicity, and Medical Care: Improving Access in a Diverse Society." This conference sought to understand the reasons for disparities in access to health and health status, and develop more effective efforts to address them. The Foundation is developing a set of "leading health indicators" by which to measure the progress made toward the elimination of disparities.
- The National Policy Association, the Association of Health Services Research, and several HHS agencies cosponsored a conference in April 2000 on "Income Inequality, Socioeconomic Status and Health: Exploring the Interrelationships." The purpose was to bring together business and labor leaders and experts in health and social policy to address critical questions about health and health disparities.



- OCR has worked closely with the United Hospital Fund, the Greater New York Hospital Associate, and the New York Task Force on Immigrant Health to develop a pilot program that used state of the art technology and trained interpreters to enable health care providers to communicate more effectively with persons who are limited English proficient.
- During the 1999-2000 legislative sessions for the States, eighteen states had pending legislation or executive orders that related to the elimination of health disparities or improving the quality of care to minorities. We are working to identify the status of these bills now that most sessions have ended.
- On April 24, 2000, HHS and the American Public Health Association announced a partnership to eliminate racial and ethnic health disparities. The partnership includes a three phase plan to develop a charge or "blueprint" of guidelines for our collaboration, develop a detailed, comprehensive national plan, and thirdly, the implementation of the plan by 2002.

#### ROLE OF THE HEALTH CARE FAIRNESS ACT OF 1999 IN IMPROVING MINORITY HEALTH

We thank you for your support of the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health, and its parallel emphasis within Healthy People 2010. The proposed Health Care Fairness Act of 1999 (H.R. 3250) addresses several of the key elements the Department has identified as essential to a comprehensive approach towards eliminating disparities:

- development of a balanced and comprehensive research agenda that addresses the unequal burden of morbidity and mortality in racial and ethnic minorities;
- supporting efforts to improve the quality and outcomes of health care services and addressing the social determinants of health, including but not limited to, access to health care;
- strengthening the data collection infrastructure of HHS;
- recognition of the important role of the Office for Civil Rights;
- support for graduate health care education curriculum development, continuing medical education efforts to reduce disparity in health and health outcomes, and increasing the knowledge base with respect to cultural competency.

We particularly appreciate acknowledgment of the importance of research into the behavioral and social factors underlying health disparities, and support programs which increase educational attainment and employment opportunities.

The section of the Health Care Fairness Act on the Office for Civil Rights is supportive of efforts underway to include the Office in development of health policy throughout HHS that address civil rights observance, program evaluation, and quality assessment.

Mr. Chairman, and members of this committee, as a physician and scientist, administrator and educator, and one charged with the task of leading the effort to challenge a health care system that allows for an unequal burden of morbidity and mortality among our racial and ethnic groups, I am reminded of how the National Institutes of Health explain how research and science work. It is said that "science" comes from the Latin *scientia* meaning "known things," scientists and the practice of science exist because of what we do not know. The aim of science is to move what we do not know into the realm of known things and then, with a greater store of knowledge, begin again, as if advancing to a new frontier.

The elimination of disparities is an achievable goal that requires we bring all our forces to bear—a balanced community health system, a comprehensive research agenda that addresses the unequal burden of morbidity and mortality in racial and ethnic minorities, training a multi-cultural workforce that is sensitive to the culture of its colleagues, data collection that reflects the inhabitants of this country, and one set of quality health care delivery goals for all. As we continue our work to improve the lives of our fellow Americans, let me leave you with the premise upon which the U.S. Public Health Service was founded in 1798, is... "to the extent we care for those most vulnerable among us, we do most to protect the health of the nation."

Thank you for the opportunity to share some of the Department's activities. We appreciate your support and look forward to continuing our partnership to improve our health care system.

Mr. BILIRAKIS. Thank you very much, Mr. Satcher.

The Chair will recognize himself for 5 minutes.

You mentioned Mr. Varmus' letter which was written after he had stepped down as Director of NIH. Believe me, it would have made our lives a lot easier if he had written it prior to that point.



You mentioned the Administration is supportive of elevating the office to Center or is it the current NIH Director or is it both?

Mr. SATCHER. The Administration, as you know within the budget submitted by the President, does not have a position on the Center proposal and so I am not speaking for the Administration in terms of the specific proposal, but as you know, the Administration is strongly supportive of strategies to eliminate disparities in health and believes that research targeted to that is critical.

Mr. BILIRAKIS. I would like to think that we are all supportive of research of that nature. What we are talking about doing is something which is apparently a little controversial, though I hate to use the word controversial. You would like to think that the people directly affected by elevating the office to center status—obviously the public is directly affected and minorities are directly affected—but I am talking about the Director of NIH and his staff, you would like to know what their position is on it. I do not think your comments go directly to that.

Mr. Ruffin, do you have any comment?

Mr. RUFFIN. In all of my conversations with the current Director of the National Institutes of Health, she is not opposed to the elevation of the office. Mr. Mark Smolonsky, who is our legislative individual there, is also accompanying me today at this meeting and if I am wrong about that in any way, then Mark can correct me, but in all of my conversations with the current Director of NIH, there has been no opposition to the elevation of the office.

Mr. BILIRAKIS. Maybe I am splitting hairs here but Mr. Jackson has also basically responded in the same way in the sense that the current Director is not in opposition but that could be sort of an ambivalence if you will. I think knowing the Directors position is significant because as I understand it if the office becomes a center, the Director may not have any control over the funding of the center—this may be acceptable but you would like to hear these things from the Director.

Mr. RUFFIN. I certainly would not be able to speak directly for the Director of NIH but again, only to translate my conversations with her on those issues.

Mr. BILIRAKIS. Does the Administration have a position on the entire bill, H.R. 3250, and if it does not have a position, will it be providing a formal position on this legislation? Can you all tell me that?

Mr. SATCHER. I cannot tell you if the Administration will submit a formal position because as I said before I think when the President submitted his budget, OMB was not in a position to speak to this particular legislation at the time.

I do want to make it clear—I obviously represent the Administration—it is my professional opinion and speaking as Surgeon General and in that responsibility for dealing with the best science, this legislation is consistent with what we are trying to do to eliminate disparities in health in this country. It is needed in order to do it.

Mr. BILIRAKIS. I agree with you, I think it is needed but I think the President of the United States should tell us the same thing, or at least the Director of NIH. I cannot quite understand, how can any of us really understand and I do not mean to slight your re-



marks and your response but it doesn't tell us what we need to hear I think.

Mr. SATCHER. So you want a statement from the Administration that it supports this specific legislation?

Mr. BILIRAKIS. Supports this legislation and if there are any areas they do not support, they should let us know and more specifically, not to belittle the other areas, but regarding the Center.

The Chair now yields to Mr. Brown.

Mr. BROWN. Mr. Satcher it is a pleasure to have you in front of us.

Your successor at CDC gives a speech about public health talking about 100 years ago the life expectancy in this country was 46 and now it is some 30 years longer. Some of the success he points out is in high tech medicine. Most of the success, 70 or 80 percent of that, the 30-year lengthening of life span, is due to strides in public health, everything from vaccines to safe drinking water to better sewage disposal, controlling of lead poisoning, seatbelts, all kinds of things like that.

Your work first at CDC and now in the Public Health Service has been exemplary. I would like you to discuss for us the disparities in public health delivery of services, whether it is inner city hospitals or vaccines or wherever you might want to go with the question. Do we know enough about these disparities in the public health part of our health care system?

Mr. SATCHER. I think we are learning more every day. These are the ten leading health indicators for Healthy People 2010. As I said, five of them are in lifestyle—tobacco use, physical activity, overweight and obesity, substance abuse, responsible sexual behavior. Five are in the health system: mental health, injury and violence, environmental quality, immunization, access to health care.

In virtually all of these areas, we can identify disparities. If you want to start with access to health care, as you know and have heard, Hispanics are most likely to be uninsured of any group in this country. One out of three Hispanics is uninsured. African-Americans are next most likely to be uninsured. Even among those who are insured, the probability of having a personal physician is lowest among Hispanics and African-Americans. Hispanics and African-Americans together make up 25 percent of the population and yet 70 percent of the people who live in underserved communities in this country.

In the area of immunization, adult immunization, influenza and pneumococcal vaccine where we are not doing as well as we should be doing with the elderly. Sixty-seven percent of whites in the last year, for which we have data, 1997, received the influenza vaccine, 67 percent of whites over 65, 50 percent of African-Americans, 58 percent of Hispanics.

In the pneumococcal vaccine, it is even worse, 47 percent whites over 65, 34 percent of Hispanics, 30 percent of African-Americans. Even in the area of environmental quality, today in this country, African-American and Hispanic children are much more likely to live within two miles of hazardous waste sites than other groups in this country. In fact, 40 percent of the people who live within two miles of hazardous waste sites in this country are African-



Americans and Hispanics. If you add American Indians, it is above 50 percent.

In all of these areas, we can point to disparities and we take the position that if we can attack these areas of disparities with the health system and we are not just talking about the health system, we are also talking about lifestyles. We have to be very clear that lifestyles like tobacco use and physical activity, substance abuse are areas of opportunity. They are not just individual responsibility. In many cases, they are community responsibilities.

If people attend schools where they do not offer courses in physical education, they are less likely to be physically active. If they live in communities where it is not safe or does not appear to be safe to get out and walk or jog on the street or bike, where you do not have biking trails, they are less likely to be physically active. In all of these areas, I think we can identify opportunities for intervention. Many of them are public health.

The only other thing I will say because I have had some minor disagreement with some of my colleagues but not major, when we say that 50 percent of disparities or variations in morbidity and mortality are due to lifestyle, 20 percent to environment, 20 percent to genetics and 10 percent to access to care, we know that a really concerned physician provider influences lifestyle significantly. If every physician would ask his or her patient if he or she smoked and then ask them to quit without even implementing a smoking cessation program, 2 million more people would stop smoking in this country every year.

If physicians wrote prescriptions like the Surgeon General's prescription, prescribing physical activity and good nutrition for their patients, many more would have appropriate lifestyles. We believe that a pediatrician who is concerned about whether his patient is exposed to lead, does the appropriate screening, intervenes with the appropriate agencies, makes a big difference in these areas. So I put a little more weight on access to care than some of my colleagues because I believe that we, as physicians, have tremendous opportunities to intervene.

Dr. Kermit Smith with the Indian Health Service can probably speak more to that than I because they have done some outstanding things in the Indian Health Service.

Mr. BILIRAKIS. The time has expired. You may have an additional minute.

Mr. SMITH. Thank you for the opportunity.

The activities we have been engaged in, our numbers might be a little bit different, access, might be a bit better but again, we have a large population of Native Americans who live in the cities and we don't deal with them in the Indian Health Service. Those that are on our reservations are in areas where we provide care and we may see only 70 to 75 percent of those who live in those areas.

We have made some real strides in the public health activities we have been involved in, sanitation. We still have areas where we have no electricity, no telephones, so in those areas we are still trying to catch up.

The activities related to smoking cessation, the behavioral activities, we have made some strides but when we look at our mortality



and morbidity, about 50 percent of the morbidity in our people is still related to behavioral activities.

Mr. BROWN. One point of clarification, going back to Mr. Satcher. You said at the beginning of your comments even among insured Americans, there is a racial disparity between whites and minorities over the number of people who actually have a primary care physician with whom they have some relationship?

Mr. SATCHER. Or even a personal physician. Ideally, that would be a primary care physician but if you just use the word personal, there are dramatic disparities.

Mr. BROWN. So minorities are less likely, even insured minorities are less likely to hear from a doctor about those issues?

Mr. SATCHER. Exactly.

Mr. BILIRAKIS. The gentleman's time has expired, Mr. Coburn?

Mr. COBURN. I just want to follow up on that. Is that because they are not available or because they don't seek them out? Where is the motivation?

Mr. SATCHER. I think that is a good question. You are going to hear some of that from the next panel. I know Kevin Schulman is here who has done some very interesting research.

This gets back to the underserved communities. You can have Medicaid or Medicare and if you live in a community where you don't have access to a physician, you are less likely to get the flu shot or even if you have a physician but don't have the kind of relationship where they really reach out to make sure you get your shot.

Mr. COBURN. You are describing a doctor instead of a physician? A physician always reaches out.

Mr. SATCHER. Especially if it is Tom Coburn.

Mr. COBURN. That is the difference and I think that is one of the things we ought to have a discussion about because part of our problem in access to care is not on the receipt end, it is on the professional side.

Mr. SATCHER. Exactly.

Mr. COBURN. We need to do a much better job in our profession of knowing what it takes to reach out to get somebody to change a lifestyle or to think about it, think about the communities. It is not just about money in terms of being a doctor.

Mr. SATCHER. I think it is significant that when you have such underrepresentation of African-Americans, Hispanics, American Indians of physicians, the cultural barriers, the reaching out, there is a difference.

Mr. COBURN. I agree.

Mr. SATCHER. That is one of our major concerns.

Mr. COBURN. My latest partner is an African-American female who graduated from Duke Medical School and she has taught me tons with my own patients culturally that I had no knowledge of in terms of interacting with them. So she has been a great benefit to teach me the cultural things. I didn't get it in medical school, that is for sure, so that is the other side of it.

I was saying we are going to have to address the professional side of this as well after you bring us the research to tell us what we need to do with this bill.



One of my favorite issues to visit with you about is what we saw on HIV and we are getting to reauthorize and we have seen this disease move to the minority communities. That is where it is shifting. Do you have recommendations for us as we do that in terms of making sure we address it because one of the things that the Inspector General and GAO reports said was "African-American, Hispanic and women are in higher proportions than the representation in the AIDS population, yet they generally receive less appropriate health care." In other words, they are there but they are not getting health care appropriate for them.

Do you have any recommendations for us, not just on this bill but as we look at what we should do on that?

Mr. SATCHER. I think it is not unrelated to what we were just discussing in terms of we know that African-Americans are less likely to be insured, we also know they are less likely to have that kind of personal physician and the kind of relationship where they are more likely to get the care they need. I think we are on the right track in looking at this whole doctor-patient relationship and making it a part of our discussion of access.

When I use the word access, I am not just talking about availability but I am talking about access to a relationship that is going to result in your getting the kind of care that you need whether it is for AIDS, which it is in this case.

We have some very, we think, good opportunities under Ryan White. When I testified we made recommendations for expanding some of those opportunities to communities that tend to get left out. We are struggling here with trying to make sure people who need a personal relationship with a physician, a caring relationship, that they are able to find it. We have to come up with some innovative strategies that might go beyond physicians to health care teams that are innovative and we may need to be a bit more aggressive in terms of some of our programs like loan forgiveness programs and things like that, loan repayment, to get more physicians into some of these communities.

Mr. COBURN. One of the things we are debating in the Ryan White reauthorization is how we allocate the money. This is a delayed disease where we have historically measured AIDS cases rather than HIV prevalence and I believe we have 33 or 34 States that have HIV prevalence data. How should we, in terms of addressing as this moves to the minority community and the communities of color, especially women because that is where it is going, how should we allocate the money? Should we use prevalence data or should we use the same old average AIDS data that we have used in the past? Do you have a recommendation in that regard?

Mr. SATCHER. I think we have to go beyond AIDS. As you know, I agree with the position and recommendation of CDC that we should have HIV name reporting. While I understand the fears of people who oppose it saying we still live in a country where you can be discriminated against in hiring, et cetera if people know you have HIV. I just think somehow we as a Nation have to guarantee the confidentiality but also the protection of people who are diagnosed as positive for HIV. I don't think we have done that yet.

I agree with you that we need name reporting and we also need to be able to track this as easily as we do other sexually trans-



mitted diseases including partner, et cetera, but in order to get there, we have to get rid of some of the fear and stigma surrounding this problem.

Mr. COBURN. We have to have a bill like this to make sure everybody has access.

Mr. SATCHER. Exactly.

Mr. BILIRAKIS. Thank you.

A vote is being called but I believe Mr. Barrett was here?

Mr. BARRETT. I will be brief.

Mr. Satcher, I want to thank you when you came to Milwaukee in December for a women's health conference and I still hear people say how wonderful you were, so I appreciate your willingness to come to the great midwest to visit with us.

Mr. SATCHER. I enjoyed being with you.

Mr. BARRETT. You will have to excuse my slow, deliberate approach but it would be helpful if you could just three illnesses or three conditions where you see a disparity between the majority community and the minority community where you think we could make a difference?

Mr. SATCHER. Let me start with infant mortality. Obviously I feel very strongly that as a Nation if there is any area where we ought to make a commitment to universal access it is to prenatal. We ought to do everything we can to make sure that every woman has access to prenatal care beginning in the first trimester of pregnancy. We talked about that this morning in terms of safe motherhood.

I believe we could make a difference if we set up systems in this country to assure that universal access to prenatal care and to really target communities because we are down to a few areas where I think we have major problems. As we said this morning, we have made dramatic progress in this country in the last 50 years in terms of reducing maternal mortality. Yet we have not made any progress since 1982. Today, African-American women are four times more likely to die during pregnancy.

While the health of the mother has a lot to do with the health of the baby, starting from the beginning of conception and even before in terms of folic acid. So we can make a lot of difference we believe in making sure every child has an opportunity for a healthy start in life in this country by really focusing on the health of the mother before and during pregnancy, access to quality prenatal care, and involvement in systems of care that even go beyond that.

I want to say diabetes because American Indians are three times more likely to suffer diabetes in this country. We spend a lot of our resources in that area treating complications like end stage renal disease, blindness and the need for lower limb amputation. I have visited hospitals on Indian reservations, very small hospitals, 24 beds and yet 30 or more people are being dialyzed for end stage renal disease.

We need to aggressively fund programs to prevent the 30 percent of Type II diabetes that we can prevent with aggressive prevention programs but also early diagnosis and tight control of diabetes. We have research showing that with early diagnosis and tight control of diabetes, we can prevent most of these complications, 90 percent



of them. We need to move to do that because we have the ability to do it.

Breast cancer is interesting. We made progress in the 1990's really for the first time in terms of cancer mortality. Actually, caucasian women in this country have the highest incidence of breast cancer.

Mr. BILIRAKIS. Forgive me a moment. Tom, we are going to have to go a bit out of order because Dr. Sullivan has a plane to catch and we have five votes which probably means a hour or close to it.

Mr. BARRETT. I would yield.

Mr. BILIRAKIS. I didn't mean that. I did want to ask if you all would not mind if we ask Dr. Sullivan to come up right now so he can give his testimony so we can hear what he has to say. We are not going to have an opportunity to question him.

Mr. SATCHER, I hate to have you cooling your heels for at least a hour.

Mr. SATCHER. I have to leave and I apologize.

Mr. BILIRAKIS. We apologize but this is the way it is up here. This is our life.

Mr. SATCHER. I feel terrible if I took time away from Dr. Sullivan.

Mr. BILIRAKIS. No, you didn't. Dr. Sullivan, please come forward. Dr. Sullivan is President of the Morehouse School of Medicine in Atlanta. He has appeared before this committee many times.

Mr. SATCHER, I don't like the idea of Ms. Eshoo and Mr. Green not having the opportunity to question you but if you have to leave, I guess you have to leave.

Ms. ESHOO. Can I just say something Mr. Chairman. I think it is really an honor to have you grace our hearing room and I salute our Chairman because he is the one that made this come about.

I would like to ask for unanimous consent that members be able to direct questions to our Surgeon General.

Mr. BILIRAKIS. Yes, written questions and you certainly don't mind that, do you? Without objection, that will be the case.

Dr. Sullivan, please proceed.

Tom, forgive me for interrupting, I know you understand.

#### **STATEMENT OF LOUIS W. SULLIVAN, PRESIDENT, MOREHOUSE SCHOOL OF MEDICINE**

Mr. SULLIVAN. Thank you, Mr. Chairman.

I am pleased to have this opportunity to appear before you on this bill that is under consideration. I will abbreviate my comments because many of the things I was going to say have been said by previous speakers but I would like to commend Congressman Jesse Jackson, Congressman Norwood, J.C. Watts, John Lewis, Bennie Thompson and Nathan Deal for their leadership and commitment to improving the health status of Americans.

Let me say that in 1985, Secretary Margaret Heckler issued a report on Black and Minority Health in the United States which among other things showed there was 79,000 excess deaths in the Nation's minority communities because of health disparities. In 1990, the Chronicle of Higher Education also pointed out that among the grants from the National Institutes of Health, less than



1 percent went to minority investigators, whether they were at majority institutions or minority institutions.

In January of last year, I was asked to testify before the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education and related agencies regarding the Institute of Medicine Study, "The Unequal Burden of Cancer." This landmark study determined that although ethnic minorities and medically underserved populations suffer disproportionately from virtually every form of cancer, the National Cancer Institute with a \$3 billion budget, committed only \$24 million or less than 1 percent of its entire budget to the study of cancer in minority populations.

Unfortunately this study reinforced what many of us have known for years, that the culture, the structure and the programs of NIH as a whole serve the majority population very well but fall short in addressing the needs of our Nation's minority populations.

The first chart is one that shows what the Chronicle of Higher Education has demonstrated. The gray areas represents the percentage of grants from NIH going to majority investigators, 89.7. The percentage going to African-American investigators is 0.4; to Hispanic investigators, 1.5; to Asian investigators, 8.1. So it shows the disparity in the granting mechanisms at NIH.

Despite the troubling findings of the IM study the Chronicle of Higher Education article and numerous other reports on minority health in our country, our society has failed to take the necessary steps to adequately address the persistent health status gaps in our Nation's population. If we as a Nation are to solve these complex problems, we must take an aggressive approach on all fronts. At the core of improving the health status of all Americans is a strong biomedical research effort aimed at understanding the factors which contribute to our Nation's health problems.

That's why when asked by Senator Specter at last year's hearing in the Senate what changes I thought were needed at NIH to improve the agency's commitment to minority health research, I recommended elevating the Office of Research on Minority Health to center status, the same that had occurred with the NIH Office of Alternative Medicine, which was elevated to the Center for Complementary and Alternative Medicine.

The Genome Project was elevated to center status and the institute status. I announced the Genome Project in 1990 during my time as Secretary. I was also pleased to work with the Congress during my time as Secretary to establish the Office of Minority Health Research. Notwithstanding the success of this office in addressing health status disparities and supporting research focused on improving minority health, the magnitude of the health status disparities problem warrants and even more aggressive approach.

Currently, this Office does not have the authority, as you've heard, to play a leadership role in advancing the priority of minority health research at NIH. I'll not go into detail—

Mr. BILIRAKIS. Doctor, could it have more authority without necessarily elevation to the center?

Mr. SULLIVAN. I think that's very difficult to do, Mr. Chairman, and my response also is this. We're talking about a problem that affects more than 25 percent of our Nation's population, one quar-



ter of our population are minorities. By the year 2050, as you know, it will indeed be half of our population.

So my position is, this is a major issue. I don't think half steps are enough. I think it should be given the full authority for grant making authority here, because we have done this in other instances.

So let me say that I applaud Congressman Jesse Jackson, Charlie Norwood and the 86 co-sponsors of their bill, 2391. This bipartisan legislation would establish at NIH the center that we have discussed.

Mr. BILIRAKIS. We have less than 4 minutes, Doctor, to make our vote.

Mr. SULLIVAN. Then Mr. Chairman, let me simply—

Mr. BILIRAKIS. Forgive me, it is with great respect.

Dr. SULLIVAN. I would like to show, as you leave, one other chart. This addresses one of the features of the bill, that is to establish the research endowments for supporting research at the Nation's four minority medical schools.

What this chart shows is the endowments at the Nation's medical schools, that shows \$1.7 billion at Harvard, \$1.3 billion at Washington University, but an average of \$133 million at the Nation's majority schools. The Nation's four minority schools have an average of less than \$10 million.

So this bill also would help to give greater capacity for research at the Nation's minority medical schools.

With that, Mr. Chairman, I thank you very much.

[The prepared statement of Louis W. Sullivan follows:]

PREPARED STATEMENT OF LOUIS W. SULLIVAN, PRESIDENT, MOREHOUSE SCHOOL OF MEDICINE

Mr. Chairman, thank you for the opportunity to testify today in support of legislation addressing the critical problem of health status disparities between our nation's majority and minority populations. I am pleased to be appear before you as President of the Morehouse School of Medicine in Atlanta, GA, and President Emeritus of the Association of Minority Health Professions Schools (AMHPS).

AMHPS is an organization comprised of the twelve (12) historically black health professions schools in the country. Combined, our institutions have graduated 60% of all the nation's African-American pharmacists, 50% of African-American physicians and dentists, and 75% of African-American veterinarians. Our member schools have a historic mission of preparing graduates to practice in medically underserved communities, and pursuing research aimed at reducing the incidence of health status disparities.

Mr. Chairman, I thank you and Congressman Brown for convening this hearing making the issue of health status disparities a priority this year. In addition, I would like to take a moment to recognize Congressmen Jesse Jackson, Jr., Charlie Norwood, J.C. Watts, John Lewis, Bennie Thompson, and Nathan Deal for their leadership and commitment to improving the health status of all Americans, particularly some of our most vulnerable citizens.

In January of last year, I was asked to testify before the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies regarding an Institute of Medicine Study entitled, "The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved." This landmark study determined that although ethnic minorities and medically underserved populations suffer disproportionately from virtually every form of cancer, the National Cancer Institute committed only \$24 million, or less than 1% of its entire budget, to the study of cancer in minority populations in fiscal year 1997.

Unfortunately, the IOM study reinforced what many of us have known for years—that the culture, structure and programs of NIH as a whole serve the majority population well, but fall short in addressing the needs of our nation's minority popu-



lations. In 1993, the *Chronicle of Higher Education* highlighted the chronic lack of support for minority health research at NIH by demonstrating that only 0.4% of the total NIH budget was dedicated to African American researchers at both minority and majority academic institutions.

Despite the troubling findings of the IOM study, the *Chronicle of Higher Education* article, and numerous other reports on minority health in this country, our society has failed to take the necessary steps to adequately address the persistent problem of health status disparities plaguing our society. If we as a nation are to solve these complex problems, we must take an aggressive approach on all fronts. At the core of improving the health status of all Americans is a strong biomedical research effort aimed at understanding the factors which contribute to our health problems.

That is why, when asked by Chairman Specter at last year's hearing what changes I thought were needed at NIH to improve the agency's commitment to minority health research, I recommended elevating the Office of Research on Minority Health (ORMH) to "center-status", in the same way that the NIH Office of Alternative Medicine was recently elevated to become the Center for Complementary and Alternative Medicine.

During the time I was HHS Secretary, I was proud to work with Congress to establish the ORMH. Notwithstanding the success of this office in highlighting health status disparities and supporting research focused on improving minority health, the magnitude of the health status disparities problem warrants an even more aggressive approach.

Currently, ORMH does not have the necessary authority to play a leadership role in advancing the interests of minority health research at NIH. For example, if the director of the Office wants to fund a research proposal he must first find another institute or center to: 1) approve the study and 2) co-fund the project. Frequently, these requirements have proven to be an insurmountable hurdle that result in many worthy minority health projects being set aside. Moreover, the director of ORMH does not have a seat at the table when the institute/center directors and the NIH leadership formally meet to set research policy and direction. If we are to see any improvement at NIH in the area of health status disparities, the director of ORMH must be in a position to help set the agency's overall minority health research agenda.

Given the challenges facing ORMH in its current form, I applaud Congressmen Jesse Jackson, Jr., Charlie Norwood and 83 additional co-sponsors for their leadership in introducing H.R. 2391. This bipartisan legislation would establish a National Center for Research on Domestic Health Disparities at NIH. I am also pleased that Congressmen Lewis and Thompson have incorporated the Jackson/Norwood legislation as Title 1 of H.R. 3250, the Health Care Fairness Act.

Under these important bills, the new National Center for Research on Domestic Health Disparities would be empowered to:

- 1) Participate fully with other institutes and centers in determining research policy at NIH with respect to minority health at NIH.
- 2) Establish a Scientific Advisory Council to assist the director of the Center in charting an institute-wide plan for minority health research for all of NIH.
- 3) Serve as a catalyst for forward-thinking, strategic planning aimed at bringing all of NIH's considerable resources to bear on the health status disparities crisis.
- 4) Make peer-reviewed grants for areas of promising research which are not being addressed by existing institutes and centers.
- 5) Establish research endowment programs at health professions institutions which have a historic mission of studying diseases that disproportionately affect minority and underserved communities. The purpose of the research endowments is to strengthen the research capabilities of these institutions.

These changes in authority will provide the new National Center with the authority and the resources it needs to make real progress toward eliminating the daunting gap in health status between white Americans and the nation's minority citizens. Anything less than these improvements will once again leave us wringing our hands over the widening gap in health status of a segment of our population that, in a few decades, will comprise the majority of people in this country. Simply stated, if we are to see meaningful, effective changes, at NIH, bold steps are necessary. I encourage the subcommittee and the Congress to establish a National Center for Research on Domestic Health Disparities at NIH this year.

Once again, thank you for the opportunity to testify this morning. I would be happy to answer any questions that you might have.

Mr. GREEN. Mr. Chairman, I have a unanimous consent request. I'd like to place in the record the Congressional Hispanic Caucus



report on Hispanic health in the United States that was done by the Caucus, and also my opening statement.

Mr. BILIRAKIS. Without objection.

[The prepared statement of Hon. Gene Green and the report follow:]

PREPARED STATEMENT OF HON. GENE GREEN, A REPRESENTATIVE IN CONGRESS FROM  
THE STATE OF TEXAS

Mr. Chairman, thank you for calling this hearing on the Health Care Fairness Act of 1999.

As a cosponsor of this bill, I am grateful for the opportunity to address minority health issues today and I commend Congressman Thompson and Congressman Lewis for their work on this initiative.

Congress needs to act this year to pass comprehensive legislation on minority health.

We should not be addressing this issue in a piecemeal fashion.

We have identified how and where research dollars should be appropriated, and we should appropriate them.

We have identified how and where access to health care is needed and we should provide that access.

Perhaps most importantly, we have identified that, although we are all Americans, we do have different cultures and those cultures must be taken into consideration when developing public policy.

A "one size fits all" approach does not work in health care research or in the provision of health care.

To be truly inclusive, we must address the needs of each of the groups that will be represented before us today.

Nowhere is this more clear than in the Houston area, including my Congressional District, where over 60% of the residents are African American, Hispanic or other minorities.

In my district, each social services agency and non-profit group uses different approaches to reach their diverse clientele. At the Montrose clinic, which assists AIDS patients, caseworkers speak close to a dozen languages including Spanish, Chinese, Arabic, Korean and Vietnamese. Patients receive services in a culturally sensitive manner.

Despite new efforts to provide such services, minorities continue to fall through the cracks of America's health care system.

Disparities in access to health care were dramatically illustrated in the recent Institute of Medicine study and we will hear more about those disparities today.

This is particularly true in urban areas such as Houston, Atlanta and Chicago. I am pleased to have joined forces with Congressman John Lewis and others to address the unique health care needs of our cities.

As we work to increase access to health care services, one of our top focuses should be on childhood immunizations—in Houston, more than 44% of children are not receiving one or more of the recommended vaccines.

During the past four years my office has held a yearly immunization clinic, where we have vaccinated over 300 children.

After talking to families at this clinic I have learned that they avoided getting immunizations in other places because they were afraid that their immigration status would be questioned or concerned about cost.

The outbreak of Measles that swept the country in 1989 began in Houston—and I am fearful that another such outbreak could occur at any time. We must do more to ensure that minority children, and all children, have access to immunizations.

In closing, I would like to give a special thanks to my colleague Ciro Rodriguez, who has been a tireless advocate for the Hispanic population throughout Texas and the United States.

As Chairman of the Hispanic Caucus Health Task Force he has done much to increase our understanding of, and attention to, the needs of Hispanic Children. I want to share with you today his report on Hispanic Health in the United States, a report that I hope you will all read and take into consideration as the legislative process moves forward.

Thank you, I yield back the balance of my time.



# Congressional Hispanic Caucus Report on Hispanic Health in the United States



April 2000

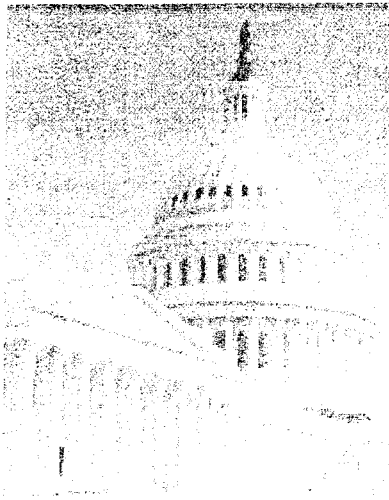
Representative Lucille Roybal-Allard, Chair, CHC  
Representative Ciro D. Rodriguez, Chair, CHC Health Task Force



## The Status of Hispanic Health

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A report on the hearings held by the  
Congressional Hispanic Caucus  
during Hispanic Health Awareness Week 1999



### Congressional Hispanic Caucus Members 106<sup>th</sup> Congress

Rep. Lucille Roybal-Allard, Chair  
Rep. Ciro D. Rodríguez, Chair Health Task Force  
Rep. Silvestre Reyes, 1<sup>st</sup> Vice Chair  
Rep. Luis Guterrez, Whip  
Rep. Matthew Martinez  
Rep. Solomon Ortiz  
Rep. Jose Serrano  
Rep. Ed Pastor  
Rep. Xavier Becerra  
Rep. Robert Menendez  
Rep. Nydia Velasquez  
Rep. Carlos Romer-Barcelo  
Rep. Robert Underwood  
Rep. Rubén Hinojosa  
Rep. Loretta Sanchez  
Rep. Charles A. Gonzalez  
Rep. Grace Napolitano  
Rep. Joe Baca



## Executive Summary

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Despite the notable progress our nation has made in the overall health of our population, serious disparities persist in the burden of illness and death experienced by minorities compared to the U.S. population as a whole. In order to educate policy makers about the health needs of the Hispanic community, the Congressional Hispanic Caucus (CHC) hosted *Hispanic Health Awareness Week* in September of 1999.

During that week, CHC members held a series of hearings on the status and specific needs of the Hispanic community in the areas of diabetes, HIV/AIDS, and mental health and substance abuse. The purpose of the hearings was to gather information from the community and educate our colleagues on Capitol Hill about the unique health needs of the Hispanic community. Public health advocates and other experts from the medical community presented research and information on these topics and offered a series of recommendations. The three hearings produced common themes regarding health care to the Latino community.

These major themes include:

### Access to Health Care

Hispanics constituted 35.3 % of the total uninsured population amounting to approximately 15.6 million people.

### Funding Needs

Funding for existing/new programs on prevention, education, and direct services should be directed towards community based organizations that serve the Latino community.

### Culturally Competent Information

Most written and verbal information that reaches Latinos is not understandable or culturally appropriate. This prevents many Latinos from receiving adequate care and from making educated decisions about their well-being.

### Representation of Latino Health-Care Professionals

A lack of adequate representation of Latinos in the health professions hinders care. Steps must be taken by the public and private sectors to increase opportunities for Latinos to enter into health professions.

### Data Collection

The U.S. Department of Health and Human Services and other federal agencies have failed to adequately collect data for Hispanics and other minority groups to determine health outcomes.





## Highlights from the Testimony Provided During Hispanic Health Awareness Week

### DIABETES

#### *Findings*

Type 2 diabetes<sup>1</sup> accounts for 90 to 95 percent of diabetes cases nationwide, and it is the most common form in the Latino community.

In the Hispanic community, type 2 diabetes occurs at a rate approximately twice that in the non-Hispanic Caucasian population. Six percent of Hispanics in the United States and Puerto Rico have been diagnosed with type 2 diabetes. It is estimated that another six percent have undiagnosed diabetes.

Latinos face numerous barriers to adequate care: lack of diabetes education; poor diet due to the unavailability and unaffordability of important vegetables, legumes and fruits; lack of exercise, due to scarce safe and community-based exercise facilities.

Controlling the risk factors of diabetes can prevent the development of diabetes in many genetically susceptible individuals. Addressing environmental risk factors like diet, weight and physical activity can significantly impact the development of diabetes.

#### *Recommendations*

Support the recommendations of the National Institutes of Health (NIH) Diabetes Research Working Group (DRWG) presented to Congress during the spring of 1999. These recommendations include: identification of genes conferring disease susceptibility in type 2 diabetes and obesity; identification of



environmental factors that may cause a predisposition to type 2 diabetes to become an overt clinical disease; increase efforts in genetic studies in minority populations.

Increase funding to Centers for Disease Control and Prevention (CDC) programs to support comprehensive awareness and education programs in all 50 states.

Provide diabetes information and messages through prime time television viewing hours, radio stations, newspapers, posters and billboards.

### HIV/AIDS

#### *Findings*

Hispanics account for 20% of new AIDS cases. Of these new AIDS cases, Hispanic men account for 20% of reported cases among



males, Hispanic women account for 19% of reported cases among females, and Hispanic children account for 22% of cases among all children.

The two primary modes for HIV transmission in the Hispanic community are: (1) individuals who have unprotected sex; (2) individuals who inject themselves with drugs.

In 1998, Hispanic women had the second-highest rate of AIDS cases among all women. Among Hispanic women, 52% of AIDS cases are from heterosexual transmission, and 44% are due to injection drug use.

Young people represent half of all new infections. Hispanic youth face risk of HIV infection from engaging in unprotected sex and/or injection drug use.

Barriers that hinder the ability to fight the disease in the Latino community include: the community's unwillingness to recognize that AIDS is a problem; lack of specific research on sexual attitudes, beliefs, behaviors and practices among Hispanics; lack of research on the factors which contribute to drug use/abuse; lack of data on Latino sub-populations; access to health care that is culturally competent; fear of seeking health care due to immigration status; lack of participation in clinical trials and research; cultural factors such as religion, views of homosexuality, "established" gender roles; language differences; level of education; limited knowledge and misconceptions about HIV/AIDS and its treatment.

The Centers for Disease Control and Prevention's (CDC) national system for HIV surveillance does not reflect the trends in the epidemic among Hispanics because currently only 33 states and jurisdictions report HIV infection cases to the CDC. For instance, California, Illinois and Puerto Rico do not

report HIV cases to the CDC, Texas reports only pediatric cases, and New York is in the process of implementing its reporting system.

#### **Recommendations**

Tailor public information and education campaigns to Hispanic sub-populations and take into account region and national origin. Provide direct, age-appropriate, and culturally-competent HIV/AIDS education. Increasing attention to youth and women should be a priority.

Increase appropriations for HIV/AIDS prevention, care services, and research.

## **SUBSTANCE ABUSE AND MENTAL HEALTH**

#### **Findings**

Mexican-American women are more likely to report severe depression than their non-Hispanic white or African-American female peers.

Adapting to a new culture is a significant factor for mental health problems and substance abuse among Hispanics.

Between 1995 and 1997, substance abuse increased among Hispanic youth at the same time it declined for non-Hispanic white and African American youth. Those at greatest risk appear to be Hispanic girls.

Hispanic girls now lead girls nationwide in rates of suicide attempts, alcohol and drug abuse, and self-reported gun possession.



*Recommendations*

Support research to assess the accessibility and quality of mental health care to all Latinos, especially for groups not well represented in current published research, such as elderly Hispanics, mainland Puerto Ricans, Cuban Americans, and Central Americans.

Ensure that prevention and treatment services are culturally-competent and appropriate.

Facilitate health and mental health access for Hispanic families through outreach in both language appropriate and culturally-competent manners.

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<sup>1</sup> *Diabetes is a chronic disease due to insulin deficiency and/or insulin action and associated with hyperglycemia. Insulin is a hormone needed to convert sugars, starches, and other food into energy essential for daily life. Type 2 diabetes, or non-insulin-dependent diabetes, develops when the body's cells resist insulin made by the pancreas and glucose remains in the blood stream.*



## Congressional Hispanic Caucus Action Plan

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The testimony received during the Hispanic Health Awareness Week hearings indicate a critical need for action at the federal level to improve research and health care delivery for Hispanics. The findings compiled from the hearings clearly portray the grim state of health care facing Hispanics. For far too long, federal resources have not been used to assess fully the health care needs of the Hispanic community nor to address the disproportionate impact diseases have on this population.

Under the leadership of Representative Lucille Roybal-Allard, CHC Chair, and Representative Ciro Rodriguez, CHC Health Task Force Chair, the Congressional Hispanic Caucus will evaluate the recommendations outlined by the health experts during *Hispanic Health Awareness Week* and develop an agenda to implement necessary changes. A major piece of this agenda will focus on ways to integrate fully the needs of the Latino community into the programs run by the U.S. Department of Health and Human Services and its agencies.

The CHC will continue to work with Members of Congress and with the Administration to eliminate health disparities in the Latino community. By eliminating the health disparities in the fastest growing population in the United States, we will help our children and improve the well-being of our country.



## Diabetes and the Hispanic Community

Wednesday, September 8, 1999

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The Congressional Hispanic Caucus (CHC) sponsored the "Diabetes and the Hispanic Community" hearing during Hispanic Health Awareness Week on September 8, 1999. Two sets of panelists testified before CHC Members about the impact of diabetes in the Latino community.

**Panel 1 participants included:**

Phillip Gordon  
Director  
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Frank Vinicor  
Director of the Division of Diabetes  
National Center for Chronic Disease Prevention and Health Promotion

**Panel 2 participants included:**

John Graham  
Chief Executive Officer  
American Diabetes Association

Yanira Cruz Gonzalez  
Policy Specialist  
National Council of La Raza

Dr. Elena Rios  
President  
National Hispanic Medical Association (NHMA)



The following is a list of findings and recommendations compiled from the testimony presented to the Congressional Hispanic Caucus:

**Findings:**

Diabetes affects an estimated 16 million Americans and its complications of the eyes, kidney, nervous system, and heart cost an estimated \$98 billion annually.

Americans with diabetes face shortened life spans. Roughly 100,000 individuals suffer preventable acute and chronic complications such as kidney failure, blindness, and lower extremity amputations each year. It contributes heavily to heart disease, birth defects, sexual impotence, incontinence, and other serious health problems.

The prevalence of retinopathy, which is a debilitating eye disease and a leading complication of diabetes, is 80% higher among Mexican-Americans than among non-Hispanic whites.

The cause of diabetes is unknown in most instances, although genetic and environmental factors appear to play a role.

Type 2 diabetes accounts for 90 to 95 percent of the diabetes case and it is the most common form seen in the Latino community.

There is an increase in reports of type 2 diabetes related to obesity and this has become a major public health concern.

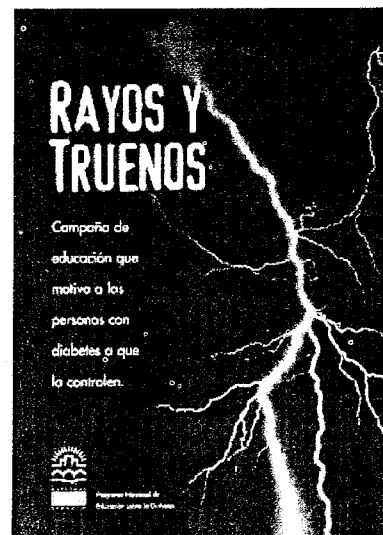
Among Hispanics, type 2 diabetes is twice as high compared to non-Hispanic whites (six percent of Hispanics in the United States and Puerto Rico have been diagnosed and it is estimated that another six percent have undiagnosed diabetes).

Among adult minority populations, 10.8% of non-Hispanic blacks, 10.6% of Mexican Americans, and 9.5% of American Indians and Alaskan Natives have diabetes.

One out of every four Mexican Americans and Puerto Ricans ages 45 and older have diabetes. One out of three elderly Latinos has diabetes.

Factors accounting for the diabetes epidemic in the US include: demographic changes (aging, increased growth of at-risk populations); behavioral elements (improper nutrition, decreased physical activity, obesity); surveillance systems that do not completely capture the exact burden of diabetes; the present inability to change unhealthy behaviors.

Diabetes disproportionately impacts racial and ethnic minority communities because: inadequate access to proper diabetes prevention and







control programs; improper quality of care; high prevalence of diabetes results in more complications such as amputations; higher critical diabetic conditions such as hyperglycemia.

Barriers to diabetes care encountered by Hispanics include: lack of diabetes education; unavailability and unaffordability of important vegetables, legumes and fruits; lack of exercise due to scarce safe and community-based exercise facilities.

Health care is key to proper diabetes care since the disease is chronic and affects multiple systems of the body, thus requiring skilled health professionals.

Controlling the risk factors of diabetes can prevent the development of diabetes in many genetically susceptible individuals. Addressing environmental risk factors like diet, weight and physical activity can significantly minimize the development of diabetes.

Patient education is critical to reduce risk for complications. Patients can learn and practice the skills necessary to better control their blood glucose levels and receive regular check-ups.

The Hispanic community's understanding of diabetes and its complications is limited. Many individuals in the community do not associate the onset of diabetes with poor nutrition, genetics, or unhealthy, sedentary lifestyles.

The American Diabetes Association's (ADA) Diabetes Assistance & Resources Program (DAR) seeks to increase the awareness in the Hispanic community about the seriousness of diabetes and the importance of prevention and control.

The ADA has increased its efforts to reach the Latino community and appointed Andrea Zaldivar to its Board of Directors.

Because the complications of diabetes affect many parts of the body this disease is an important trans-National Institutes of Health (NIH) research area.

The NIH has a two-step peer reviewed process to identify the most promising avenues of diabetes research: an initial review by a group of non-Federal scientists and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Advisory Council.

The NIDDK has undertaken research initiatives to fight diabetes. Large-scale studies of the genetics of diabetes and the genetic susceptibility to diabetic kidney disease are forthcoming. NIDDK's efforts include the establishment of the National Task Force on Prevention and Treatment of Obesity, since obesity is a serious risk factor for type 2 diabetes. In addition, NIDDK has formed the International Type 2 Diabetes Linkage Analysis Consortium to map genes responsible for type 2 diabetes.

Two clinical trials conducted by NIDDK are: (1) Diabetes Prevention Program, which is







HHS's Diabetes Work Group, co-chaired by CDC and NIH, has identified ways to address the gaps of what is known about diabetes, and develop strategies to eliminate the disparity.

CDC's efforts to fight the diabetes epidemic in the Latino community include: developing a national strategy to increase awareness and education, promoting early detection services about diabetes; funding of state based control programs; building partnerships to broaden the message.

CDC has initiated a 5 year study to conduct research within managed care organizations that will evaluate and improve the health care and health status of people with diabetes.

CDC funds state-based diabetes control programs in all 50 states, the District of Columbia, and eight US affiliated island jurisdictions. A two-tiered funding level enables 34 states to operate core capacity-building diabetes programs and 16 states to operate comprehensive capacity-building programs.

#### **Recommendations:**

Support the recommendations of NIH's Diabetes Research Working Group (DRWG) presented to Congress during the spring of 1999. These research efforts include: identification of genes conferring disease susceptibility in type 2 diabetes and obesity; identification of environmental factors converting predisposition to type 2 diabetes into overt clinical disease; efforts to increase genetic studies in minority populations.

Support DRWG recommendations to tackle diabetes in racial and ethnic minority communities. These recommendation include: initiate research to develop culturally sensitive preventive and therapeutic approaches utilizing innovative communication and education techniques applicable in "real world" settings

such as rural and county clinics, and urban health centers; design and conduct studies in partnership with minority communities to better understand the cultural, familial, and other factors that influence the adoption of health promotion and to change high risk behaviors.

Increase NIH's recruitment and training of Latinos in areas related to diabetes.

Promote the inclusion of Hispanics in major clinical studies to reach population-appropriate conclusions.

Increase funding to CDC programs to support comprehensive awareness and education programs in all 50 states.

Provide diabetes information and messages through prime time hours, radio stations, newspapers, posters and billboards.

Provide funding for community-based organizations and community and migrant health care centers for diabetes education and treatment programs.

Request information from the CDC regarding: status of the recommendations produced by the National Hispanic/Latino Diabetes Initiative for Action; status of the University of Illinois





and the Promotora Diabetes Initiatives targeting Latinos.

Request that the Health Care Financing Administration (HCFA) develop standards that address quality of health care for diabetics.

Request that the Food and Drug Administration (FDA) continues its "Take Time to Care" campaign to use medications effectively.



## HIV/AIDS and the Hispanic Community

Thursday, September 9, 1999

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The Congressional Hispanic Caucus (CHC) sponsored the "HIV/AIDS and the Hispanic Community" hearing during Hispanic Health Awareness Week on September 9, 1999. Two sets of panelists testified before members of the CHC about the impact of HIV/AIDS in the Latino community.

**The Panel 1 participant was:**

Dr. David Satcher  
United States Surgeon General

**Panel 2 participants included:**

Barbara Aranda-Naranjo, RN, Ph.D  
Member, Presidential Advisory Council on HIV/AIDS  
University of the Incarnate Word, San Antonio, Texas

Martin Ornelas-Quintero  
Executive Director  
National Latina/o Lesbian, Gay, Bisexual & Transgender Organization (LLEGO)

Miguelina Maldonado  
Director of Government Relations  
National Minority AIDS Council (NMAC)

Ruth Roman  
Policy Specialist  
National Council of La Raza (NCLR)



The following is a list of findings and recommendations compiled from the testimony presented to the Congressional Hispanic Caucus:

**Findings:**

Hispanics account for 20% of new AIDS cases. In terms of new AIDS cases, Hispanic men account for 20% of reported cases among males, Hispanic women represented 19% of reported cases among females, and Hispanic children made up 22% of cases among all children.

In 1997, AIDS was the third leading cause of death among Hispanics between the ages of 25 and 44, and the 10th for Hispanics of all ages.

The AIDS rate among Hispanic men is 3.3 times greater than white men, while Hispanic women have an AIDS case rate almost 7 times higher than their white counterparts. Hispanic children have an AIDS case rate almost five times that of white children.

Among migrant farm workers, HIV prevalence is estimated between 3 and 13%. Multiple health problems and high mobility make delivering consistent medical care to this population very difficult.



The Status of Hispanic Health

The two primary modes HIV is spreading among Hispanics are: (1) Individuals who have unprotected sex (46%); (2) Individuals who inject themselves with drugs (39%).

In 1998, Hispanic women had the second-highest rate of AIDS cases among all women. Among Hispanic women, 52% of AIDS cases are from heterosexual transmission and 44% are due to injection drug use.

The fastest growing number of HIV cases is among women (23% of new cases).

Young people represent half of all new infections. Hispanic youth faces risk of HIV infection from engaging in unprotected sex and/or injection drug use.

Hispanic adults are almost eight times more likely than non-Hispanics to be illiterate; therefore, traditional means of disseminating disease prevention messages and healthy lifestyle recommendations often don't reach them.

Prevention is one of the challenges to halt the spread of the HIV/AIDS epidemic.

Despite the advances in AIDS drug therapies that have led to drops in AIDS deaths, ethnic and racial minorities continue to lag behind. Between 1996 and 1997, deaths due to AIDS dropped 54% for whites, 44% for Hispanics, and 38% for African Americans.

Barriers that hinder the ability to fight the disease in the Latino community include: the community's unwillingness to recognize that AIDS is a problem; lack of specific research on sexual attitudes, beliefs, behaviors and practices among Hispanics; lack of research on the factors which contribute to drug use/abuse; lack of data on Latino sub-populations; access



to health care that is culturally competent; fear to seeking health care due to immigration status; lack of participation in clinical trials and research; cultural factors such as religion, views of homosexuality, "established" gender roles; language differences; level of education; limited knowledge and misconceptions about HIV/AIDS and its treatment.

#### The HIV

Care Services Utilization Study (HCSUS) shows that many Hispanics learned of their HIV status later in the course of the disease and were referred into care later. Once in care, Hispanics were less likely to receive appropriate antiretroviral therapies.

Latinos have a higher rate of concern about HIV infection than other ethnic groups and this could be utilized to educate, motivate and mobilize community members.

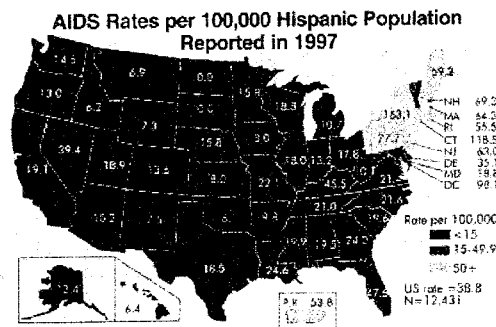
Even when Latinos are aware of the risk factors for HIV/AIDS, they tend not to translate these risks as affecting them personally.

The Centers for Disease Control and Prevention's (CDC) national system for HIV surveillance does not reflect the trends in the epidemic among Hispanics because currently only 33 states and jurisdictions report HIV infection cases to the CDC. For instance, California, Puerto Rico and Illinois do not report HIV cases to the CDC, Texas reports

only pediatric cases, and New York is in the process of implementing its reporting system.

HIV reporting data must be used with caution

and surrogate markers for HIV infection (rates of infection from other sexually transmitted diseases and teen pregnancy rates) should be used to project trends and to target funding.



#### CDC's allocation

of prevention-related resources do not reflect the current epidemiological trends (support for programs targeting racial and ethnic minorities, injection drug user populations, and men who have sex with men).

CDC's HIV/AIDS budget in FY99 indicates that about 9.9% (\$35 million) of \$353 million is targeted specifically to Hispanics.

#### Recommendations:

Encourage national, regional and local leaders to increase their involvement in the fight against HIV/AIDS.

Develop a national initiative to encourage testing. The initiative should target high-risk population groups.

Coordinate national testing campaign with local HIV Prevention Community Planning grants so that funds are linked to local demographics of the epidemic.





Direct CDC to target resources to community based organizations in the Hispanic community for HIV prevention services. Populations reached by these CBOs include: gay men, youth, women, injection drug users, immigrant and migrant populations.

Tailor public information and education campaigns to Hispanic sub-populations and take into account region and national origin.

Provide direct, age-appropriate, culturally-competent education. Increase attention to youth and women.

Encourage participation of minorities in the planning groups created by CDC's HIV Prevention Community Planning, which is the primary process to get federal funding for prevention activities.

Increase appropriations for HIV/AIDS prevention, care services, and research.

Provide funding for CBOs and National Regional Minority Organizations to develop culturally-sensitive appropriate materials.

Strengthen the Communities of Color Initiative.

Increase funding for international HIV program.

Increase funding for programs that seek to deliver capacity building assistance (CBA) to HIV prevention programs and services.

Commit resources to standardize data collection procedures and conduct continuous analysis and reporting of Latino data.

Explore techniques such as behavior modification to prevent HIV infection.

Support the Ryan White CARE Act.

Advocate for access to care and funding for early intervention through expansion of Medicaid.

Include/develop a comprehensive system approach to the care of Latinos living with HIV infection.

Direct the Health Resources and Services Administration (HRSA) to develop and expand initiatives aimed at training Hispanic health professionals on current HIV treatment and care.

Direct HRSA to standardize and regulate the formularies used by the states to access AIDS Drug Assistance Program (ADAP).

Work with the Substance Abuse and Mental Health Services Administration (SAMHSA) to increase access to substance abuse treatment for Hispanics.

Request a report from CDC to establish the initiatives and resources allocated to serve the Hispanic community.

Request a report from CDC to delineate its plans to address the under-representation of Hispanics in Prevention Community Planning. The plan should address the disparities in the allocation of HIV prevention resources and ensure that states are channeling resources to populations with the greatest need for prevention services.



## Mental Health and Substance Abuse

Thursday, September 9, 1999

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The Congressional Hispanic Caucus (CHC) sponsored the "Mental Health and Substance Abuse and the Hispanic Community" hearing during Hispanic Health Awareness Week on September 9, 1999. Two sets of panelists testified before members of the CHC.

### **The Panel 1 participant was:**

Dr. Nelba Chavez  
Administrator  
Substance Abuse and Mental Health Services Administration (SAMHSA)

### **Panel 2 participants included:**

Dr. Jane Delgado  
President  
National Coalition of Hispanic Health and Human Services Organizations  
(COSSMHO)

Dr. Rosa Gil  
Special Advisor to the Mayor for Health Policy  
Office of the Mayor of New York City

Dr. Steve Lopez  
Professor  
University of California at Los Angeles



The following is a list of findings and recommendations compiled from the testimony presented to the Congressional Hispanic Caucus:

**Findings:**

SAMHSA is a model agency with several programs serving the Hispanic community: SAMHSA has launched new efforts to provide better service to Hispanic customers including six substance abuse prevention products developed by the Hispanic community.



SAMHSA sees data collection as an important component of adequate health care and provides technical assistance to States to improve the quality of the data collected as part of the Substance Abuse Prevention and Treatment Block Grant and for the Community Mental Health Services Block Grant.

SAMHSA has sponsored the development and distribution of national radio public service announcements in Spanish to help educate Latino youth and adults on the dangers of alcohol abuse.

SAMHSA has provided training in cultural competency among substance abuse treatment providers.

SAMHSA has sponsored a Minority Fellowship program to increase the pool of ethnic minority doctoral level mental health professionals and researchers as well as increased service and prevention activities for ethnic minority individuals with mental health and substance abuse disorders.

Mexican-American women are more likely to report severe depression than their non-Hispanic white, or African-American female peers.

53% of Hispanic women responded to a survey that they were seriously depressed, in comparison to 37% of non-Hispanic white and 47% of African American women.

Adapting to a new culture is a significant factor for mental health problems and substance abuse among Hispanics.

Substance abuse increased among Hispanic youth at the same time that it declined for non-Hispanic white and African American youth. Those at greatest risk appear to be Hispanic girls.

Recent immigrants are less likely to engage in risky activities than acculturated youth.

Acculturation itself is also tied to increased rates of attempted suicides and depression among Hispanic girls, boys, and adults.

Hispanic girls now lead girls nationwide in rates of suicide attempt, alcohol and drug abuse, and self-reported gun possession.

Close to one out of every three Hispanic female high school students in 1997 had seriously considered suicide in comparison to one out of every five African American girls and one out of every four non-Hispanic white girls.



Hispanic female students are almost twice as likely to have experimented with cocaine than their non-Hispanic white counterparts and over twelve times as likely as their African American peers.

Fewer prevention or treatment services reach Hispanic girls than girls in any other racial or ethnic group.

Little is known about whether mental health services are reaching Latino children.

Hispanic girls are significantly less likely to have been taught about risks of HIV/AIDS in school than their African American and non-Hispanic white peers.

There is a critical lack of trained professionals who speak Spanish. This is a serious problem when it comes to evaluating the needs of bilingual children.

#### ***Recommendations:***

Set aside resource allocations to include Hispanics in all HHS programs and tailor services to the cultural needs of the Hispanic population.

Put all Hispanic Caucus recommendations into the Hispanic Agenda for Action.

Support research to assess the accessibility and quality of mental health care to all Latinos, especially for groups not well represented in current published research, such as elderly Hispanics, mainland Puerto Ricans, Cuban Americans, and Central Americans.

Make housing a component in addressing the mentally ill.

Ensure that investigators, directors, and staff have the experience and qualifications to work



with Hispanics to develop programs to recruit and train Hispanics in health professions.

Continue working to increase and make available educational programs that develop medical, behavioral, and research careers for Hispanics.

Hire staff who speak Spanish and are knowledgeable of Latino culture.

Provide incentives for mental health systems of care to train existing practitioners and administrators to incorporate treatments that have proven effective with Latinos.

Provide incentives for educational institutions to recruit and train practitioners who are able to communicate in Spanish at a professional level.



Provide incentives for educational institutions to carry out systemic training in treating Latinos with mental health problems.

Provide incentives for the test industry to improve available tests for Latinos, in general, and limited English proficient Latinos, in particular.

Encourage local health agencies to partner with local health professional programs at colleges and universities to increase the pool of eligible health professionals adequately trained to work with the Hispanic community.

Increase the availability and affordability of adequate health insurance for Hispanics.

Ensure that prevention and treatment services are culturally competent and appropriate.

Ensure that any public media campaign taking place is accompanied by culturally competent community-based prevention treatment programs.

Ensure health and mental health access for Hispanic families through outreach in both language appropriate and culturally competent manners.

Provide language appropriate and culturally sensitive programs to prevent child abuse.

Support research to test cultural and linguistic translations of available evidence-based treatments so that they can be used by Latinos.

Encourage local health agencies to thoroughly evaluate the cultural and linguistic competence of their programs, management and clinical staff. This would reduce the barriers to care and enhance accurate diagnosis and successful treatment interventions.

Encourage local health agencies to sponsor cultural sensitivity seminars designed to enhance the knowledge-base of administrators and direct service providers in culturally competent services in the Hispanic community.

Emphasize the need for performance-monitoring and data that evaluate areas of success to identify effective programs. Adequate resources for these programs should be provided.

Improve data collection on risk resiliency factors facing Hispanic girls and boys paying attention to Hispanic subgroups and geographic location.

Support successful community-based strategies to promote resiliency among Hispanic girls and boys to strengthen Hispanic families.

Support new community-based models to promote positive cultural identification and adaptation among Hispanics to reduce the serious risk to Hispanic girls in particular.

Provide child care services while parents seek treatment.

Provide incentives for mental health systems of care to apply existing organizational technology to make services accessible to Latinos.

Encourage local health agencies to include health consumers in the planning of services.



Our special thanks to the following organizations and federal agencies:

- U.S. Department of Health and Human Services Office of the Surgeon General
- Centers for Disease Control and Prevention, Division of Diabetes
- National Institutes of Diabetes and Digestive and Kidney Diseases
- Substance Abuse and Mental Health Services Administration
- Presidential Advisory Council on HIV/AIDS
- American Diabetes Association
- National Hispanic Medical Association
- National Council of La Raza
- National Minority AIDS Council
- National Latina/o Lesbian, Gay, Bisexual and Transgender Organization
- National Coalition of Hispanic Health and Human Services Organizations
- City of New York, Health Policy Office

*To obtain a copy of the written testimonies submitted  
to the Congressional Hispanic Caucus during  
Hispanic Health Awareness Week,  
log onto <[www.house.gov/rodriguez/](http://www.house.gov/rodriguez/)> or call (202) 225-1649.*



Mr. BILIRAKIS. And I would hope that we all would have an opportunity to read Dr. Sullivan's testimony. It's very powerful.

Mr. BROWN. Mr. Chairman, if anyone has questions to submit to Dr. Sullivan, I'm sure we could——

Mr. BILIRAKIS. Yes, without objection, I'm sure you're willing to——

Mr. SULLIVAN. Oh, yes, I'd be pleased to.

Mr. BILIRAKIS. Thank you so much for being here, Doctor. Forgive me for treating you this way, but you know what it's like here.

Mr. SULLIVAN. I understand. Thank you very much.

Mr. BILIRAKIS. Well, we're going to have to adjourn for anywhere from 45 minutes to an hour, depending on how long it takes us to address five votes.

[Brief recess.]

Mr. GREENWOOD [presiding]. I'll preside briefly.

Do we have all our witnesses here? All right, if the witnesses could take their seats, we'll see how many of them we don't have.

Upon further consideration, apparently the Subcommittee Chairman has indicated that at 10 after 2, we would reconvene in an hour. So we'll reconvene at 10 after.

[Brief recess.]

Mr. GREENWOOD. The hour of 2:10 having arisen, we will start and assume that the other witnesses will hear your eloquent testimony and come running in. I'll introduce panel three, is that correct? We have Dr. Gilbert Friedell, Director for Cancer Control, Markey Cancer Center, University of Kentucky, testifying on behalf of the Institute of Medicine. We have Dr. Jordan Cohen, President and CEO of the Association of American Medical Colleges. Dr. Kevin Schulman is Associate Professor of Medicine and Director of the Center for Clinical and Genetic Economics, Duke University Medical Center. Dr. Anne Peterson is not here yet. Dr. John Harley is a member and program head of the Oklahoma Medical Research Foundation.

Mr. Friedell, if you would start us off, please.

**STATEMENT OF GILBERT H. FRIEDEL, DIRECTOR EMERITUS, MARKEY CANCER CENTER, UNIVERSITY OF KENTUCKY; MEMBER, INSTITUTE OF MEDICINE COMMITTEE ON CANCER RESEARCH AMONG MINORITIES AND THE MEDICALLY UNDERSERVED**

Mr. FRIEDEL. Thank you, Mr. Chairman. I'm delighted to be here, and appreciate the opportunity to testify.

I'm speaking here on behalf of the Institute of Medicine Committee, which provided this report on the Unequal Burden of Cancer: An Assessment of NIH Research and Programs For Ethnic Minorities and the Medically Underserved. I stress those last few words, because so far much of the comment has been about minority health, where the report for NIH was something a little broader than that.

Much of what I wanted to say has been said, so I'll be brief about my remarks. As you all know, one in four deaths in the country are attributable to cancer, expected to become the leading killer in the next century. People have referred to some of these numbers, but I'll repeat them that African American men are more likely to be



diagnosed with prostate cancer than white men. Asian Americans are more likely to develop stomach and liver cancer. Cervical cancer is higher among Hispanic and Vietnamese American women. African American women, though less likely to develop breast cancer are less likely to survive it.

I would point out, though, that the highest incidence in mortality rates for lung cancer are in the rural, poor population in Appalachian Kentucky. And Native Americans have the lowest cancer survival rates of all.

The key question, then, for researchers and public health officials, is why these differences in cancer incidence, mortality and survival persist. The 15 member committee that I served on looked at these questions, assessed how NIH prioritizes cancer research among minority and medically underserved populations, how it applies research findings to prevention and treatment. We looked at the adequacy of procedures related to including minorities in clinical trials, and the communication of these results to the general public.

I'd like to make five particular points this afternoon summarizing some of these major findings, and you'll appreciate, these are five brief points out of a report of several hundred pages. No. 1, better surveillance efforts are needed to provide a more complete picture of the burden of cancer among minority and medically underserved individuals. The report, you understand, was about cancer, not about health in general.

Second, research is needed on the reasons for the disparities as reflected by the burden of disease data generated by cancer surveillance. Third, that research is particularly needed on the medically underserved, a category which cuts across race and ethnicity. Four, as currently constituted, neither the Office of Special Populations Research at NCI nor the Office of Research on Minority Health at NIH have the authority, budget or other support mechanisms to effectively coordinate, stimulate and facilitate research for minorities and medically underserved groups. And five, the target for reducing cancer mortality would be achieving the lowest rates of cancer mortality for selected cancers seen among different populations. And I'll elaborate briefly on each of those points.

The first one about surveillance, a critical first step is to pinpoint exactly what differences exist among racial and ethnic groups, as well as socioeconomic groups. By legislation, the National Cancer Institute's Surveillance Epidemiology End Results program is charged with this responsibility as far as cancer is concerned, by monitoring incidence of mortality and survival rates. It's the closest thing we have to a national report, but it's severely limited in a few areas.

Several groups are not covered in the SEER program. In order for it to be most effective, the committee recommended it should be expanded to include populations not covered, such as lower income or poverty level whites, especially those living in rural areas, for example Appalachia; Hispanics of all national origins; African Americans living in rural communities, particularly the south; and the American Indian population. Furthermore, the results should be correlated with the State cancer registries that are being devel-



oped under the CDC program of the National Program Cancer Registries.

As far as disparities are concerned, we believe NCI should give consideration to the magnitude of the cancer problems in different ethnic groups. The research needs of these groups and of medically underserved groups could be identified primarily on the burden of disease which is found in each of these populations. Without setting boundaries to begin with of race and ethnicity, let's look at the burden of disease which is found by inadequate surveillance program. This was the gist of one of our recommendations.

Third, while a disproportionately large share of African Americans and Hispanics live at or below the poverty level, poor whites, particularly the rural poor, constitute the largest group of poverty level individuals. According to the U.S. Bureau of the Census, in 1996, there were approximately 10 million African Americans, approximately 7 million Hispanics, approximately 1.3 million Asians or Pacific Islanders, 714 million American Indians and almost 22 million whites living below the poverty line. These individuals suffer from rates of disease and disability as high or in some cases higher than racial and ethnic minorities and should be a higher priority in NIH's research efforts.

Insofar as the Office of Research on Minority Health is concerned, we believe NIH needs to formulate a blueprint or coordinated plan for addressing questions related to minorities and the medically underserved. Within NCI, the Office of Special Populations Research is charged to serve as the Director's eyes and ears on research needs of minority groups, the low income and low literacy populations, the blue collar workers and other populations considered to be at a higher risk for cancer. But this office lacks the authority and the resources to coordinate an extensive program of research among ethnic minorities.

Similarly, the Office of Research on Minority Health, which is to coordinate the studies on ethnic minority health problems, but its impact also is limited by the size of its budget and its lack of authority over NIH research programs. It has no involvement, furthermore, with the medically underserved who are not recognizable by race or ethnicity. That office should more actively coordinate, plan and facilitate cancer research relevant to ethnic minorities and medically underserved populations across NIH centers and institutes.

Insofar as reducing cancer mortality by achieving the lowest rates of cancer mortality for selected cancers, what we mean by this is that there are low rates of some cancers. For example, prostate cancer among Chinese, high rates among African Americans. We suggested that it would be important to look at those populations that have low rates of cancer as well as looking only at the populations that have high rates of cancer.

My more extensive remarks have been submitted to the Committee. I would like to point out two particular things, though, that may be relevant. One of them is that there's been much discussion about various rates of diseases beyond cancer in minority populations. A few months ago, the Lexington Herald Leader produced a supplement which relates to health disorders in Appalachian or Eastern Kentucky, a 99 percent rural white population. You'll find



on reading this that the rates for diabetes, hypertension, coronary heart disease and some cancers are almost as high, in some cases higher, than rates that have been reported for recognizable minorities. I think this may be an important thing for the group.

In addition, there may be some reprints of specific issues which perhaps I could add to the Committee's files later. But the bulk of my testimony really relates to the IOM committee report. Thank you very much.

[The prepared statement of Gilbert H. Friedell follows:]

PREPARED STATEMENT OF GILBERT H. FRIDELL, DIRECTOR EMERITUS, MARKEY  
CANCER CENTER, UNIVERSITY OF KENTUCKY

Good morning Chairman Bilirakis and members of the Subcommittee. On behalf of the entire IOM Committee on Cancer Research Among Minorities and the Medically Underserved, I am pleased to be here today to present our report.

One in four deaths in this country is attributable to cancer, which is expected to become the country's leading killer in the next century. Recent scientific gains have fueled the first overall reduction in deaths from cancer, but not all groups in the U.S. population have seen an improvement. Poor people and some ethnic minorities are more prone to certain types of cancer and are less likely to survive it than the rest of the population.

African-American men, for example, are more likely to be diagnosed with prostate cancer than white men. Asian Americans are more likely develop stomach and liver cancer. Cervical cancer is higher among Hispanic- and Vietnamese-American women. African-American women, though less likely than others to develop breast cancer, are also less likely to survive it. Further, lower-income whites in rural areas such as Appalachia have some of the highest rates of specific types of cancer in the country. And Native Americans have the lowest cancer survival rates of all.

A key question for researchers and public health officials is why these differences in cancer incidence, mortality, and survival rates persist.

The 15-member Institute of Medicine committee that I served on examined these questions, and assessed how the National Institutes of Health (NIH) prioritizes research on cancer among minority and medically underserved populations and how it applies research findings to prevention and treatment programs. We also looked at the adequacy of procedures related to including minorities in clinical trials, as well as the communication of research results to these groups and other key issues to the public. In the report, published in January, 1999, we offered recommendations that we hope not only will help improve the health of minorities and the medically underserved, but everyone in our increasingly diverse society.

A critical first step is to pinpoint exactly what differences exist among racial and ethnic groups, as well as socioeconomic groups. By legislation, the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program is assigned the responsibility of assessing the burden of cancer in the population by continuously monitoring cancer incidence, mortality, and survival rates. It is the closest thing the country has to a longitudinal national cancer database, but its usefulness is diminished by limitations in the way data are collected.

Unfortunately, several key groups are not adequately covered in the SEER program. In order for this program to be most effective, the committee recommended it should be expanded to include populations not covered, such as lower-income or poverty level whites, especially those living in rural areas such as Appalachia; Hispanics of all national origins; African Americans living in rural communities, particularly in the South; and American Indian populations. Further, this database should be coordinated with newer state databases to create a national registry with uniform methods of data collection and analysis.

In accordance with the guidelines of the federal Office of Management and Budget, NIH classifies the population into one of four racial categories—White, Black, Asian or Pacific Islander, or Native American. This method of classification was not intended for epidemiological research and, in fact, is not consistent with current scientific thinking. There are no known biological boundaries that justify the division into races.

We recommend that NCI place a greater emphasis on the differences in cancer among ethnic groups and those of low socioeconomic status, with a view to determining the roles that diet, lifestyle, and customs play in varying rates of cancer. We need to take advantage of the ethnic diversity of the American population to



explore, for example, why Chinese American men have such low rates of prostate cancer compared with African American men.

Overall, we believe that NIH needs to formulate a blueprint or a coordinated plan for addressing questions related to cancer among minorities and the medically underserved. NIH's Office of Research on Minority Health coordinates studies on ethnic minority health problems, but its impact is limited by the size of its budget and other constraints, and it has no involvement with the medically underserved who are not recognizable by race or ethnicity. That office should more actively coordinate, plan, and facilitate cancer research relevant to ethnic minorities and medically underserved populations across NIH centers and institutes. Within the National Cancer Institute, the Office of Special Populations Research lacks the authority and resources to coordinate an extensive program of research on cancer among ethnic minorities. This office should be given greater authority to expand NCI's research in these areas.

NCI also should improve its estimates of the money it spends on the health needs of minorities and the medically underserved. NCI reported spending about \$124 million in fiscal year 1997 for research and training programs addressing cancer in these populations. NCI's estimate is derived by calculating the percentage of minorities enrolled in research studies. We believe that NCI should base its estimate on the research questions involved rather than on the percentage of minorities in its studies. Such a coding procedure would allow NCI to accurately provide data on the number of studies that pose research questions specifically designed to better understand the burden of cancer among minority and medically underserved populations, and the amount of funds allocated to these studies. When one considers the greater burden of cancer among minorities and the increasing diversity of the U.S. population, NCI's current allocation is too low.

In setting research priorities, NCI places strong emphasis on research that capitalizes on scientific opportunities, and rightly so. However, we believe that NCI should give consideration to the magnitude of the cancer problem in different ethnic groups. The research needs of ethnic minority and medically underserved groups should be identified on the basis of the burden of disease in these populations, with an assessment of the most appropriate areas of research. These areas of needed research may be stimulated by requests for applications or other targeted efforts from NIH institutes.

Participation in clinical trials among minorities has improved in recent years, to the point where their participation in NCI-sponsored cancer treatment trials is proportionate to the burden of disease in these populations. However, participation in prevention trials remains low. The absence of minorities in some of these trials—for example the recently concluded tests of tamoxifen to prevent breast cancer in women at high risk for the disease—raises questions about how applicable the results are to minority populations.

As NIH and NCI continue to review strategies for communicating with the public, they should give special attention to the needs of ethnically diverse and medically underserved communities. Among the key issues that remain is how to obtain truly informed consent from research subjects who experience language and literacy barriers.

NIH should establish a formal system of reporting to Congress and the public on cancer studies for ethnic minorities and medically underserved groups. Reports should include details on the number and type of research programs specifically targeted to these groups, and the contributions of ethnic minority scientists and community groups representing minorities and the medically underserved to the research priority-setting process. At the same time, NCI should improve efforts to disseminate information about cancer to patients, clinicians, and others in ethnic minority and underserved populations, and create a system to assess effectiveness. Cancer survivors from these groups should be tapped as important resources for educating others in their communities about cancer.

Finally, the committee concluded that the diversity of the American population offers a great opportunity for exploring all of the possible causes of cancer. For example, we asked what might happen if all Americans had the same rate of cancer at each site as the lowest rate of any ethnic group. For example, if all Americans had the low rate of lung cancer as Hispanics, mortality due to lung cancer would be reduced by 50 percent. This is not to suggest that those groups that experience low rates of some forms of cancer should not be the focus of our research and prevention efforts; rather, research on the dietary patterns, lifestyles, and health behaviors of lower-risk groups offers an opportunity to improve the health of higher-risk groups. It is a goal worth pursuing as long as there were not promises of quick results.

Throughout our study, the National Cancer Institute was generous in providing the information that we requested, and it is clear to us that NCI is undergoing dy-



namic change. In fact, some of our suggestions for improvement today have already been suggested internally at NCI and are in the process of being implemented. We commend NCI's plans to increase its commitment to behavioral research, especially if some of that research is specifically targeted toward minorities and the medically underserved.

The National Cancer Institute is a great national resource that is vigorously pursuing the goal of reducing cancer in America. From the beginning of the "War on Cancer" it has been forced to grapple with the continuous demand for quick results. There was even a strong notion that the problem of cancer would be solved by 1976. But we now know that there are no quick fixes in cancer research. A big breakthrough is often the result of years of patient and sometimes unrecognized effort. Cancer is not one but more than 100 diseases. We hope our recommendations will help NCI and all of NIH tackle this difficult health problem in order to further the health of all Americans.

Mr. GREENWOOD. Thank you very much for your testimony, sir.  
Dr. Cohen.

**STATEMENT OF JORDAN J. COHEN, PRESIDENT AND CEO,  
ASSOCIATION OF AMERICAN MEDICAL COLLEGES**

Mr. COHEN. Thank you very much, Mr. Chairman, members of the Committee. My name is Jordan Cohen, and I'm President of the Association of American Medical Colleges, which represents U.S. medical schools and major teaching hospitals in our country, medical students, residents and faculty.

The Association is pleased to endorse the Health Care Fairness Act, H.R. 3250, and we commend the Committee for holding this hearing. We must do more as a country to find solutions to the existing critical disparities in health status and access to quality health care among significant segments of our Nation's population.

While it is important that everyone involved in providing health care to patients work to eliminate health disparities, medical schools and teaching hospitals have a unique responsibility both to integrate the knowledge of these disparities into the education of physicians and the delivery of health care, and to ensure that these problems are high on the research agenda, historically the AAMC has taken a leadership role in addressing issues related to inequalities and disparities in medicine. We have played an active role in enhancing the diversity of those providing health care and assisting our member institutions to advance the teaching and education and evaluation of cultural competence.

AAMC supports the establishment of a center for research on minority health at the National Institutes of Health, and the development of a comprehensive research plan for all minority health research at the NIH in consultation with other NIH institutes and centers. The causes of health disparities are complex, and include a mix of socioeconomic, cultural and behavior factors, as we learned from Dr. Satcher earlier today.

Few, if any, diseases are unique to particular racial or ethnic groups. But patterns of prevalence, as we've heard, and of severity, differ widely in various racial and ethnic populations. Research on minority health issues should be incorporated into the mission of each of the NIH institutes and centers, building on the scientific and clinical expertise that resides in their programs.

The bill also authorizes the submission of the center's budget directly to the President and to Congress. Traditionally, the Association has not supported the creation of such a separate budget by-



pass for specific areas of research. However, the critical need to enhance the research efforts to address minority health disparities is sufficient, in our view, to justify making an exception in this case to our longstanding policy opposing bypass budgets.

AAMC has consistently and strongly advocated additional funding for the NIH's effort to attract and retain more under-represented minorities into careers in biomedical and behavioral research. AAMC supports the establishment of centers of excellence for research as another positive initiative to achieve a more diversified research work force. We also believe that any institution with a well documented and sustained commitment to addressing issues of minority health should be eligible for these awards.

The Association is especially pleased with the provisions in Title IV on medical education, which will enable health professional schools to enhance and expand existing programs to address cultural competency. In particular, we note that the legislation would provide support for increased curricula and faculty development for cultural competency at all levels of health professions education, including continuing education.

In conclusion, we believe that the disparities in health status as a function of race and ethnicity are among the most pressing challenges that confront our Nation. AAMC thanks the Subcommittee for holding this hearing to examine these issues, and urges Congress to move forward when considering and passing H.R. 3250.

Thank you very much.

[The prepared statement of Jordan J. Cohen follows:]

PREPARED STATEMENT OF JORDAN J. COHEN, PRESIDENT AND CEO, ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges (AAMC) is pleased to have this opportunity to testify in support of the Health Care Fairness Act, H.R. 3250. Representing the nation's 125 accredited allopathic medical schools, nearly 400 major teaching hospitals and health care systems, 91 academic and professional societies representing more than 87,000 faculty members, and the nation's 167,000 medical students and residents, the AAMC commends the subcommittee for holding this hearing. Our country must do more to find solutions to the existing, critical disparities in health status and access to quality health care among significant segments of this nation's population.

The AAMC, whose overarching mission is the improvement of the health of the nation, is deeply concerned about these disparities. While it is important that everyone involved in providing health care to patients work to eliminate health disparities, medical schools and teaching hospitals have a unique responsibility to integrate knowledge of these disparities into the education of physicians and the delivery of health care, and to ensure that these problems are high on the research agenda. Historically, the AAMC has taken a leadership role in addressing issues related to inequalities or disparities in medicine. We have played an active role in enhancing the diversity of those providing health care and in assisting our member institutions to advance the teaching and evaluation of cultural competence.

For more than 30 years, the AAMC and its member medical schools and teaching hospitals have committed themselves to increase the racial and ethnic diversity in the medical profession, including establishing a division within the AAMC to address minority issues, sponsoring workshops highlighting the importance of noncognitive variables (e.g., leadership, determination, altruism, compassion, maturity, coping capabilities, communication skills) in the admissions process, promoting the development of a minority affairs infrastructure within medical schools, creating two AAMC Task Forces to identify problems and solutions related to increasing minority enrollment, launching in 1991 Project 3000 by 2000, and most recently, organizing and staffing the Health Professionals for Diversity coalition.

The AAMC is pleased to endorse the Health Care Fairness Act, H.R. 3250, which identifies a series of pressing issues that affect the health of a significant portion of our nation's population. We believe that the disparities in health status and ac-



cess to health care among various racial and ethnic groups result from multiple causes, and that the multiple solutions proposed in this legislation are needed to eradicate these inequities.

The AAMC supports the establishment of a Center for Research on Minority Health at the National Institutes of Health (NIH) and the development of a comprehensive research plan for the conduct and support of all minority health research at the NIH in consultation with all other NIH institutes and centers, as called for in Title I of the bill. The causes of health disparities are complex and include a mix of socioeconomic, cultural, and behavioral factors. Few if any diseases are unique to particular racial and ethnic groups, but patterns of prevalence and severity differ widely in various racial or ethnic populations. Accordingly, the AAMC believes that research on minority health issues should be incorporated into the mission of each of the NIH institutes and centers, building upon the scientific and clinical expertise that resides in these programs. The NIH's success is based on its ability to marshal the full weight of all of its institutes to solve fundamental scientific questions and to address the most urgent challenges of disease.

We note that Title I also authorizes the submission of the Center's budget directly to the President and Congress. Traditionally, the Association has not supported the creation of such a separate budget by-pass for specific areas of research. However, the critical need to enhance the research efforts to address minority health disparities is sufficiently to justify making an exception to our long-standing policy opposing by-pass budgets.

The AAMC has long been concerned about the need to attract and retain more underrepresented minorities into careers in biomedical and behavioral research, and has consistently and strongly advocated additional funding for the NIH's efforts in this area. The AAMC supports the establishment of Centers of Excellence for Research as another positive initiative to achieve the goal of a more diversified research workforce. We also believe that any institution with a well-documented commitment to addressing issues of minority health should be eligible for these awards. The bill states that eligible institutions must have significant numbers of minority students and faculty without defining what is meant by significant. We would suggest that this wording be modified so as not to leave the impression that research on minority health issues is, or should be, the concern only of minority researchers. We look forward to an opportunity to work with members of the subcommittee to assure that this program will be designed to encourage as many institutions as possible to develop substantive programs of research in these areas.

The Association is especially pleased with the provisions in Title IV on medical education, which will enable health professions schools to enhance and expand existing programs to address cultural competency. In particular, we are pleased to note the legislation would provide support for increased curricula and faculty development for cultural competency at all levels of health professions education, including continuing education. These programs will complement and enhance the AAMC's education initiatives, including the dissemination of specific objectives for medical education, the recognition by accrediting bodies on the importance of requiring the inclusion of cultural issues in the curriculum, and the mounting of faculty development activities to enhance the teaching and evaluation of cultural awareness.

The bill also authorizes an information clearinghouse for curricula to reduce racial and ethnic disparities in health care and health outcomes, and a national conference on continuing health professions education as a method to reduce such disparities. The AAMC believes that both of these initiatives will promote greater dissemination of successful efforts to reduce health disparities.

In conclusion, the disparities in health status as a function of race and ethnicity are among the most pressing challenges that confront us as a nation. The AAMC thanks the subcommittee for holding this hearing to examine these issues and urges Congress to move forward in considering and passing H.R. 3250.

Mr. GREENWOOD. Thank you, Dr. Cohen, very much, for your testimony.

Dr. Schulman.

**STATEMENT OF KEVIN A. SCHULMAN, ASSOCIATE PROFESSOR OF MEDICINE AND DIRECTOR OF THE CENTER FOR CLINICAL AND GENETIC ECONOMICS, DUKE UNIVERSITY MEDICAL CENTER**

Mr. SCHULMAN. Mr. Chairman, thank you, and Mr. Brown, and other members of the Committee.



Thank you very much for inviting me to appear before the Committee today. I want to try and provide a framework and rationale for the medical education sections of the Health Care Fairness Act, especially Section 201, which refers to grants for medical education curriculum development.

Medical literature has carefully documented racial and ethnic differences and the use of medical therapies for patients with many conditions. We've heard a lot on this today. One point to emphasize here is that these differences in treatments have been shown to result in differences in patient survival in and of themselves.

One issue not addressed by this entire body of literature is whether physicians who are contributing to these differences are making different treatment recommendations based on patient race and sex. We explored this concept directly in a major study published last year in the *New England Journal of Medicine*.

We assessed physicians' treatment recommendations for simulated patients who differed from each other only on the basis of race and sex. We include eight patient actors in the experiment, 4 black, 4 white, 4 male and 4 female. Their pictures are included in the testimony I submitted to the Committee.

Overall, we found that for identical patients, physicians were less likely to refer blacks compared to whites, and women compared to men, for cardiac catheterization, and that the lowest referral rates were for black women. Further, we were able to show that these results were not influenced by patient personality.

In addition, the physicians rated the black patient actors of being of lower socioeconomic status than the white patient actors, despite the fact that all patients had identical job descriptions, lived in the same location, were dressed in the same clothing and had the same health insurance.

In this carefully controlled experiment, we were able to demonstrate that patients' characteristics influenced physician's recommendations for cardiac catheterization. The social psychology literature suggests that all of us characterize new individuals when we meet them using an automatic or subconscious process. These characterizations incorporate societal attitudes and stereotypes into a label that we attach to other people.

The absence of bias indicates an ability to consciously override these automatic characterizations in relating to other people. Our experiment suggests that a brief interview with a new patient may not yield sufficient information to override these automatic characterizations. These subconscious characterizations may then contribute to physicians' treatment recommendations for identical patients observed in our study.

The implication of this study is a disturbing one, that physicians are contributing to disparities in health care between blacks and whites in this country. This is not to say that physicians' actions are responsible for all or even a majority of the racial disparities in medical treatment that have been observed. In fact, we cannot assess the relative contributions of the many factors shown to affect differences in procedure utilization across patient race. In addition, we haven't looked at Hispanics or other races in our experiment.



However, any contribution by physicians to these disparities cannot be tolerated, as Mr. Coburn said this morning.

While disturbing, these results also offer us hope. As Thurgood Marshall said, what you have to do, white or black, you have to recognize that you have certain feelings about the other race, good or bad, and get rid of them. But you can't get rid of them until you recognize you have them.

The medical education section of the Health Care Fairness Act offers an opportunity to directly address this issue. The legislation will allow us to develop new educational programs to target the subconscious biases that seem to explain a reversible component of the disparities in health care between blacks and whites. Finding the optimal method of implementing such a sensitive curriculum is an issue of major concern that would be addressed in the research effort called for in this legislation.

The public will not be assured that the health care system is truly blind to race until we are able to show that these training programs are effective. Hence, the importance of the evaluation component of these grants. These evaluation efforts will allow us to understand what works in developing cultural competency curricula, and to rapidly disseminate effective programs to other sites. In this increasingly multicultural society, the issue of how to ensure that patient characteristics no longer influence clinical decisionmaking is of critical importance in designing medical school residency and continuing education curricula, and ensuring appropriate clinical practice.

Thank you very much for asking me to present here with you today.

[The prepared statement of Kevin A. Schulman follows:]

PREPARED STATEMENT OF KEVIN A. SCHULMAN, ASSOCIATE PROFESSOR OF MEDICINE,  
DIRECTOR, CENTER FOR CLINICAL AND GENETIC ECONOMICS, DUKE UNIVERSITY  
MEDICAL CENTER

Mr. Chairman and distinguished members of the Committee: Thank you very much for inviting me to appear before the Committee today. I want to try to provide a framework and rationale for Title II of the Health Care Fairness Act of 1999, specifically section 201, which refers to grants for medical education curriculum development.

Large-scale epidemiologic studies have reported race and sex differences in management of patients with chronic diseases in the United States. In the vast majority of these studies, investigators have found that blacks are less likely than whites to undergo procedures in both inpatient and outpatient settings. Let me first review some of these data with you.

In a recent article, we reviewed more than 30 major epidemiologic studies assessing differences in cardiac procedure utilization rates between blacks and whites. While these studies varied in the number of patients included, in the types of data analyzed, and in the specific clinical conditions under assessment, almost all found that blacks compared to whites were less likely to undergo cardiac catheterization, cardiac angioplasty, or coronary artery bypass surgery.

While disturbing, these epidemiologic studies did not suggest either the reasons for differences in clinical practice or the implications of these differences for individual patients. Many of the authors felt that underlying structural factors within the health care system were responsible for the major portion of their findings, including differences in access to private health insurance. However, certain portions of this body of research suggest that insurance coverage is not the only reason for differences in access to procedures. In an important study of patients within a single health care system—the Veterans Health Administration—Dr. Eric Peterson found results similar to those reported in other epidemiologic studies; yet all patients at VA medical centers had the same insurance program, which eliminates insurance as an explanation for these differences. Similarly, Bruce Vladeck found, when he



was Administrator of the Health Care Financing Administration, that black patients within the Medicare program were less likely than white patients to undergo cardiac procedures, again providing evidence that differences in insurance coverage do not fully explain the differential use of procedures in blacks compared to whites.

Even with the important information that insurance may not be the only factor responsible for differences in access to procedures, controversy continued about whether differential access results in worse outcomes for minority patients. Dr. Peterson subsequently developed data that suggest that differences in mortality between blacks and whites exist even after adjustment for clinical factors, but are no longer apparent when differences in treatment between blacks and whites are included in statistical analysis. This was one of the first studies to demonstrate that differences in access to care result in differences in survival for a specific population of patients.

Unfortunately, as we have looked beyond cardiovascular disease, we have found differences in access to other major medical procedures for blacks compared to whites, including the treatment of stroke patients and the use of bone marrow transplantation for patients with leukemia and lymphoma. In an important paper late last year, Dr. Peter Bach of Memorial Sloan-Kettering Cancer Center found that blacks compared to whites were less likely to undergo surgical resection for early-stage, non-small-cell lung cancer. Furthermore, Dr. Bach was able to demonstrate that differences in mortality between black and white patients were directly related to differences in surgical therapy received by those patients.

Another significant study contributing to this field looked at patients with end-stage renal disease. The study examined whether patients with end-stage renal disease in the Medicare program were referred for evaluation for kidney transplantation. Once again, black patients compared with white patients were less likely to be referred for surgical procedures. In this study, however, the authors were also able to directly assess patients' desires for kidney transplantation. The authors reported that differences in patients' desires between blacks and whites did not explain differences in access to transplant evaluation.

Dr. William Owen at Duke University Medical Center looked at patients undergoing dialysis at outpatient dialysis centers across the country. He found that blacks compared to whites were less likely to receive optimal doses of dialysis in 1993. However, through careful monitoring and feedback using clinical guidelines and clinical performance measures, this disparity in care was almost eliminated over a four-year period. Dr. Owen's study provides some evidence that physicians are contributing to disparities in care between blacks and whites.

We explored this concept directly in a major study published last year in the *New England Journal of Medicine*. We were especially interested in exploring whether physicians contributed to differences in procedure rates among blacks and whites by assessing physicians' recommendations for simulated patients who differed from each other only on the basis of race and sex. Using a computer survey instrument, we presented groups of practicing physicians with clinical cases that varied from each other only on the basis of six patient variables, including patient age, race, sex, type of chest pain, cardiac history, and stress test results. Eight trained patient actors—four blacks, four whites; four men, four women; four 55-year-olds, four 70-year-olds—were asked to record three identical interviews representing three distinct types of chest pain. We then asked 720 primary care physicians to interview one of the eight patient actors by reviewing one of 24 video segments. In this study, a total of 144 different cases were available for assessment by individual physicians.

Overall, we found that for identical patients, physicians were less likely to refer blacks compared to whites and women compared to men for cardiac catheterization, and that the lowest referral rates were for black women. In an extensive series of analyses, we were able to show that these results were not influenced by patient personality. In addition, the physicians uniformly rated the black patient actors as being of lower socioeconomic status than the white patient actors, despite the fact that all patients had identical job descriptions, lived in the same locations, were dressed in the same clothing, and had the same health insurance.

In this carefully controlled experiment, we were able to demonstrate that patients' characteristics influence physicians' recommendations for cardiac catheterization.

The social psychology literature suggests that all of us characterize new individuals when we meet them using an automatic process. These characterizations occur subconsciously and incorporate societal attitudes and stereotypes. The absence of prejudice indicates an ability to consciously override these automatic characterizations.

Our experiment suggests that a brief interview with a new patient may not yield sufficient information to override these automatic characterizations. These sub-



conscious characterizations may then contribute to physicians' treatment recommendations for identical patients observed in our study.

The implication of these studies is a disturbing one: that physicians are contributing to disparities in health care between blacks and whites in this country. This is not to say that physicians' actions are responsible for all or even the majority of the racial disparities in medical treatment. In fact, we cannot assess the relative contributions of the many factors shown to affect differences in procedure utilization across patient race. However, any contribution by physicians to these disparities can not be tolerated.

The results of the studies I have reviewed suggest that physicians—though dedicated professionals—are similar to everyone else in society in that they may harbor subconscious attitudes and biases toward groups. These attitudes and biases, even at the subconscious level, may manifest themselves inadvertently when physicians make different treatment recommendations based solely on characteristics such as race. But these results also offer us hope and the opportunity to improve ourselves. As Thurgood Marshall said, "What you have to do—white or black—you have to recognize that you have certain feelings about the other race, good or bad. And then get rid of 'em. But you can't get rid of them until you recognize them."

How do we get rid of subconscious biases in the case of the individual physician? The potential for subconscious bias to influence clinical decision-making is a much more difficult topic to address from an educational and regulatory perspective than overt bias would be under civil rights law. There are currently no compelling studies that test and demonstrate the efficacy of particular approaches to this problem in medical education. While the American Medical Association has recently called for initiatives to increase awareness of racial disparities—in medical school curricula, medical journals, professional conferences, and peer review activities—only a small minority of U.S. medical schools reported that they had a cross-cultural competency component to their curriculum. In a recent survey of U.S. medical schools, only 13 of the schools responding to the survey reported offering a course designed to explain the delivery of health care in ethnically diverse populations.

Even in those medical schools that have implemented a "cross-cultural curriculum," there are no data regarding the effectiveness of current educational approaches. The need to explore the potential for cross-cultural education to reduce subconscious biases on the part of clinicians was recently highlighted in a study published in the *American Journal of Medicine*. In the study, when interviewing identical patients with identical complaints of chest pain, the participating medical students overall rated the quality of life lower for a 55-year-old black woman than for a 55-year-old white man, despite the fact that the students thought the black woman had less severe heart disease. It seems that our medical students are entering medical school with subconscious biases about patients, the same biases we revealed in our 1999 study of practicing physicians.

The medical education section of the Health Care Fairness Act of 1999 offers tremendous hope to the millions of Americans who have been deeply affected by these studies. The bill calls for the development of grants for medical education curriculum development and for research projects and demonstration projects to develop curricula designed to reduce disparities in health care outcomes, including faculty development and cultural competency programs for graduate and undergraduate medical education. These grants will allow us to develop new educational programs to target the subconscious biases that seem to explain a reversible component of disparities in health care.

Adequately addressing this issue will require self-awareness on the part of individuals regarding their own perceptions and biases, and a willingness to find ways of overcoming these biases in both working with and treating patients. Finding the optimal method of implementing such a sensitive curriculum is an issue of major concern that would be addressed through the research effort called for in this legislation.

Finally, the public will not be assured that the health care system is truly "blind" to race until we show that these training programs are effective; hence, the importance of the evaluation components of these grants. These evaluation efforts will allow us to understand what works in developing cultural competency curricula and to rapidly disseminate effective programs to other sites.

In this increasingly multicultural society, the issue of how to ensure that patient characteristics no longer influence clinical decision-making is of critical importance in designing medical school, residency, and continuing education curricula and in ensuring appropriate clinical practice. We have observed differences in treatment resulting in differences in survival for patients with cardiovascular disease and lung cancer. Our previous work suggests that physicians contribute to these differences by making different treatment recommendations based on patient race. Yet students



in most medical schools today are not taught about issues of race or how their own subconscious biases may interfere with access to treatment. The Health Care Fairness Act of 1999 offers a first step to ensuring that all patients will be offered equal access to life-saving medical therapy, regardless of their race. The American public should expect no less from its health professionals.

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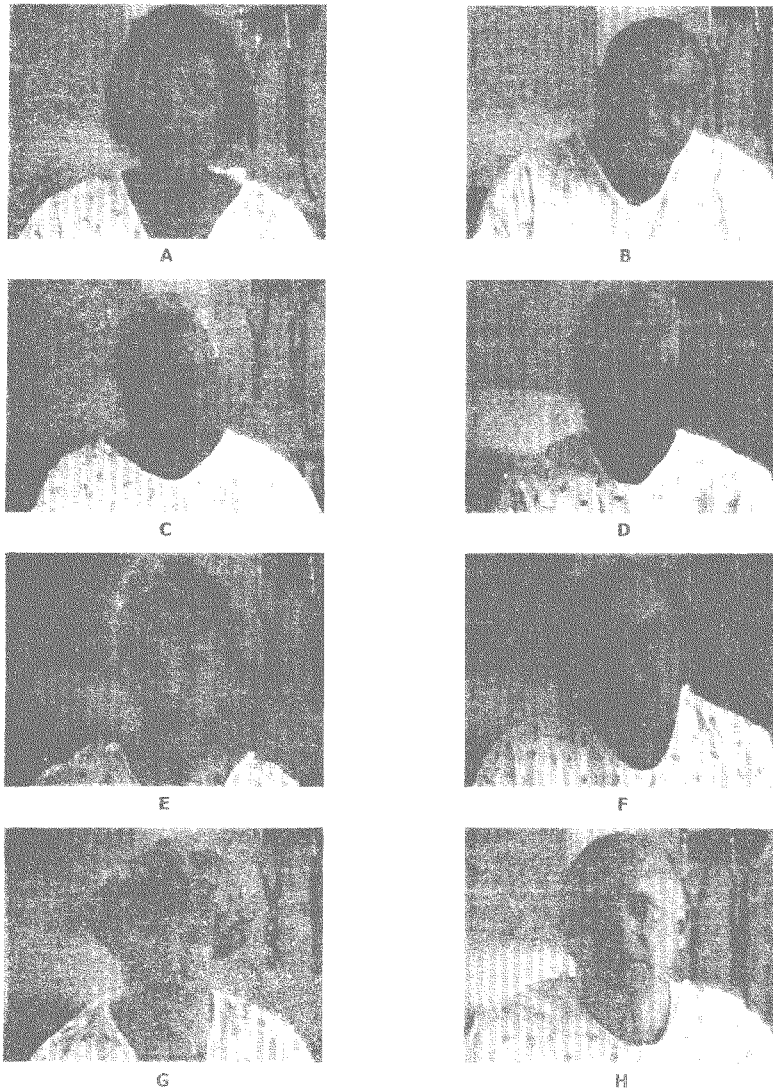
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**Figure 1.** Patients as portrayed by actors in the video component of the survey.

Panel A shows a 55-year-old black woman, Panel B a 55-year-old black man, Panel C a 70-year-old black woman, Panel D a 70-year-old black man, Panel E a 55-year-old white woman, Panel F a 55-year-old white man, Panel G a 70-year-old white woman, and Panel H a 70-year-old white man.

**Figure 1: Patient Actors**





Mr. BILIRAKIS. Thank you very much, Doctor.  
 Dr. Anne Peterson, Health Commissioner for the Commonwealth of Virginia. Welcome, Dr. Peterson.

**STATEMENT OF ANNE PETERSON, HEALTH COMMISSIONER,  
 COMMONWEALTH OF VIRGINIA**

Ms. PETERSON. Thank you very much, Mr. Chairman and members of the Committee.

I am the State Health Commissioner for Virginia, and perhaps in bringing a different perspective, some of which the questions came up earlier today that I hope to be able to address. Virginia is both recognizing many areas of racial disparities and beginning to address them in some very significant ways.

We established an office of minority health in 1992, and we are developing partnerships between the private and public sector to establish goals to improve the health of all Virginians, with a focus on eliminating disparities. Dr. Satcher spoke about the Healthy People 2010. Virginia set eliminate disparities as part of our Healthy People 2000 goals. So we've been looking at that for quite a while already.

We have a major initiative within that office on access to care. On June 20, 21 and 23 and have a forum on access to care for minority health this summer. One area, and this is the one I was asked to discuss today, where minorities have clearly been disproportionately affected, is HIV/AIDS. While African Americans comprise only 20 percent of Virginia's population, they account for almost two-thirds of the reported HIV cases in Virginia, and over half of the reported AIDS cases. Minority females have been particularly hard hit by this disease. Although African American women account for only 20 percent of the female population of Virginia, they represent over three quarters of the female HIV cases in Virginia and almost three quarters of all the female AIDS cases.

While these statistics are alarming, we are making progress. By careful analysis of the HIV reporting data, Virginia was one of the first States to recognize that HIV and AIDS were disproportionately affecting the minority community. As a result of that early recognition of the minority disparity trend, Virginia has initiated efforts to directly address this disparity, and we are already beginning to see some results. Analysis of Virginia's surveillance data does not show that racial or gender disparity for the length of time between HIV diagnosis and AIDS.

In other words, minority males and females are progressing from initial HIV diagnosis to sickness at a similar rate as whites. The number of AIDS deaths for minorities is also decreasing, after peaking in 1995, AIDS deaths have decreased substantially for both African Americans and whites. Initially the deaths decreased more markedly for whites than African Americans. With the addition of the 1999 data, the reduction of deaths among African Americans were comparable to those of whites. This may indicate that more minorities were able to access appropriate and timely care.

Providing anti-retroviral treatment to pregnant women with HIV infection has also significantly decreased the transmission of HIV to their newborns. This is particularly important to minority health since of the perinatal HIV cases reported in Virginia for 1995 to



1999, 79 percent of the babies were African American. Since 1995, when Virginia law required that all physicians encourage pregnant women in their care to receive HIV testing, and if indicated, treatment, over 90 percent of the HIV infected pregnant women have been tested. In 1991, 91 percent of the infected mothers were treated with anti-retroviral medication and pre-natal transmission has decreased from 20 cases in 1992 to 2 so far this year.

In closing, while Virginia has addressed disparities among minorities with HIV and AIDS, we are also focusing on primary prevention and other sexually transmitted diseases. An example is the syphilis elimination project, which uses a two-pronged approach of community involvement to assist prevention and education and train public health staff to identify and treat the disease. The National Centers for Disease Control and Prevention recently conducted a site visit to Danville, Virginia, and plans to use our efforts as a model for other States to follow.

So I would just say, as you look at research and as we get data on health disparities and understand the risk factors, we then can, as this example shows, focus our resources and begin to make a difference in closing the disparity gap.

Thank you for this opportunity.

[The prepared statement of Anne Peterson follows:]

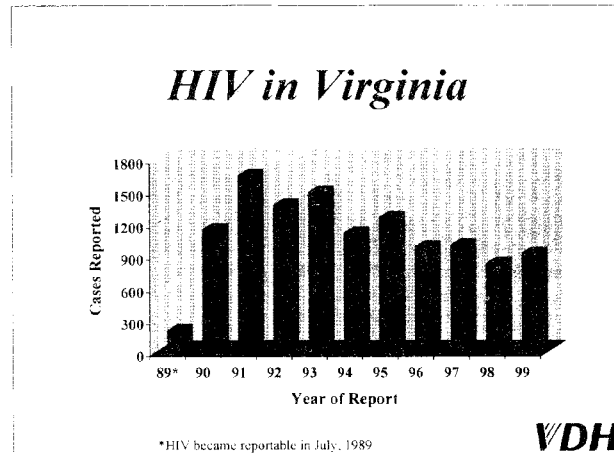


# **HIV/AIDS**

## **Trends and Minority Health Disparities**

### **Virginia**



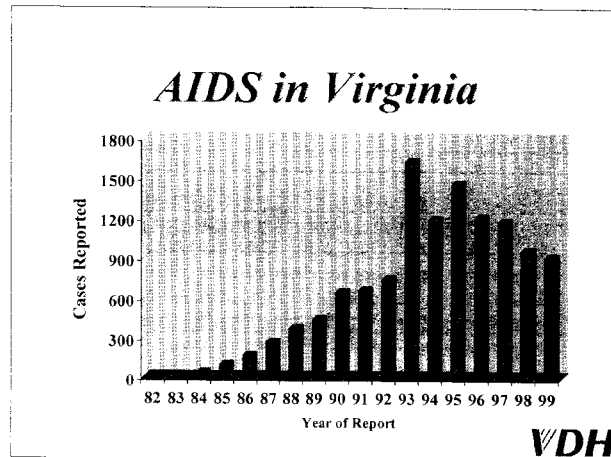


HIV Reporting was mandated in July 1989.

After remaining virtually level for 1996 and 1997, the number of reported HIV cases decreased 17% to 825 in 1998, the lowest number since the first year of reporting in 1989.

Reported HIV cases increased 11% (918) in 1999, due primarily to additional validation studies conducted by the Division of HIV/STD.

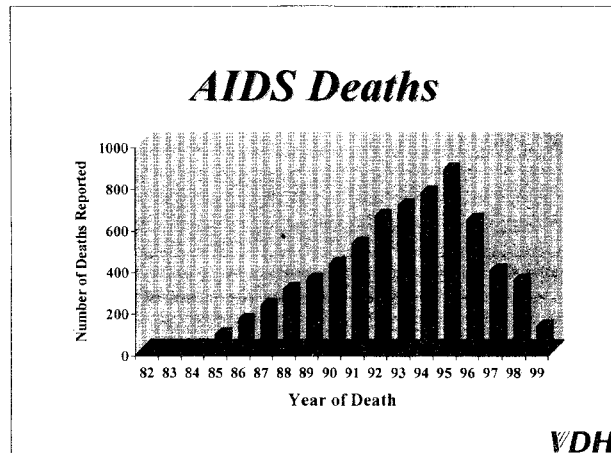




The number of reported AIDS cases peaked in 1993 at 1629 cases. This is also the year CDC changed the AIDS case definition.

Reported cases of AIDS totaled 1459 for 1995 and have since continued a downward trend. In 1999, there were 910 reported AIDS cases. This represents a 38% decrease during the past five years.

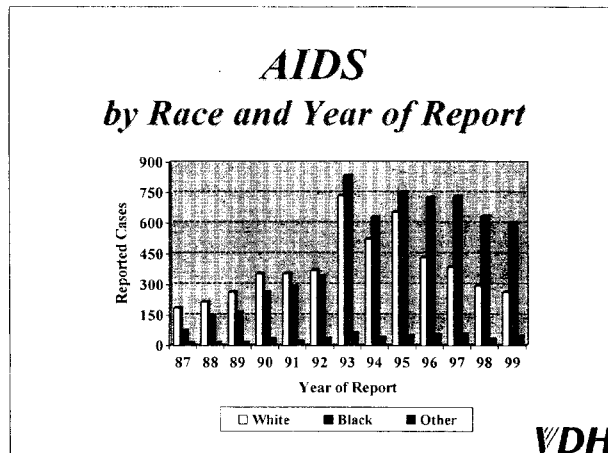




Reported AIDS deaths continued to increase every year from 1983 - 1995. The peak in 1995 totaled 873 deaths.

Since 1995, deaths from AIDS have dropped considerably from 631 deaths in 1996 to 338 in 1998. For 1999, there are currently 116 reported deaths. This represents a 87% decrease from 1995.



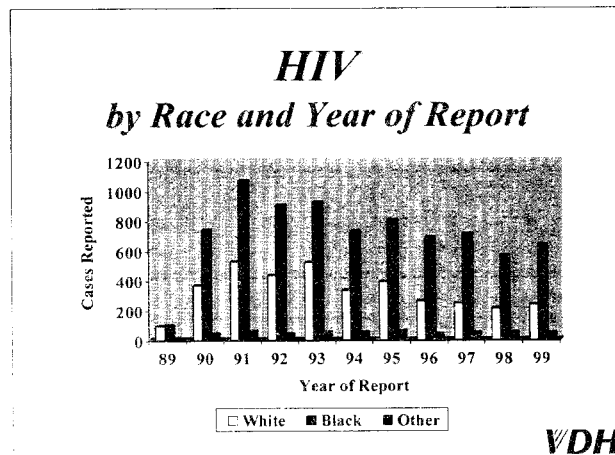


Whites accounted for the largest percentage of reported AIDS cases until 1993 when African Americans were reported with 833 cases compared to 736 White cases.

In 1995, African Americans accounted for 52% of all reported AIDS cases (Whites: 45%). In 1998 the percentage of cases among African Americans increased to 66% (Whites: 31%).

In 1999, the percentage of reported AIDS cases among African Americans decreased 4% compared to 1998 to 62% of all cases (Whites: 29%).



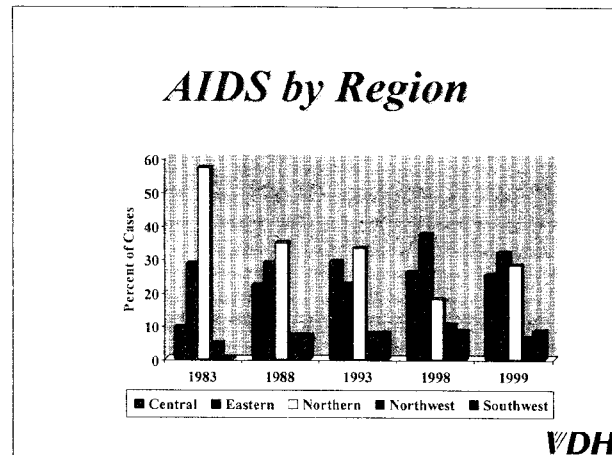


The number of African Americans reported with HIV has exceeded Whites since HIV reporting began in July 1989.

In 1998, reports of HIV among African Americans accounted for 69% of cases (Whites: 26%).

In 1999, African Americans also accounted for 69% of all cases (Whites: 26%).



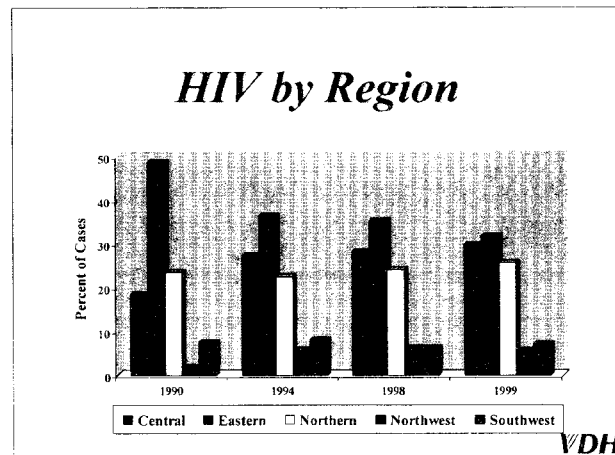


Cumulatively, the Eastern region makes up the largest percent of total reported AIDS cases (31%) followed by Northern (29%) and Central (24%).

In 1998, Central had the highest rate per 100,000 at 22 followed by Eastern (21) and Northwest (11). Virginia's rate was 14.

Reported AIDS cases peaked in Northern in 1993 (538 cases), Eastern in 1995 (552 cases), Central in 1993 (476 cases), Northwest in 1993 (125 cases) and Southwest in 1995 (151 cases).





Cumulatively, the Eastern region makes up the largest percent of total reported HIV cases (39%) followed by Central (26%) and Northern (21%).

In 1998, Central had the highest rate per 100,000 at 20, followed by Eastern (17) and Northern (12). Virginia's rate was 12.

Reported HIV cases peaked in all regions except Northern in 1991 (Eastern - 592, Central - 496, Southwest - 172, Northwest - 117). Northern's cases peaked in 1993 with 375 cases.



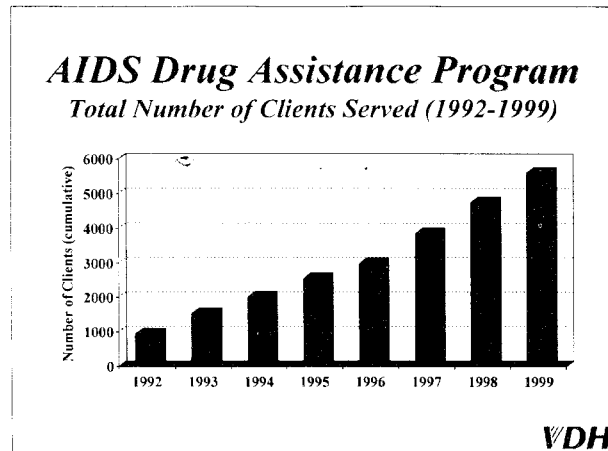
# **AIDS Hot Spots In Virginia**



93

This thematic map represents a general overview of reported case proximity by individual cities/counties.  
Color variation does not represent specific case location.



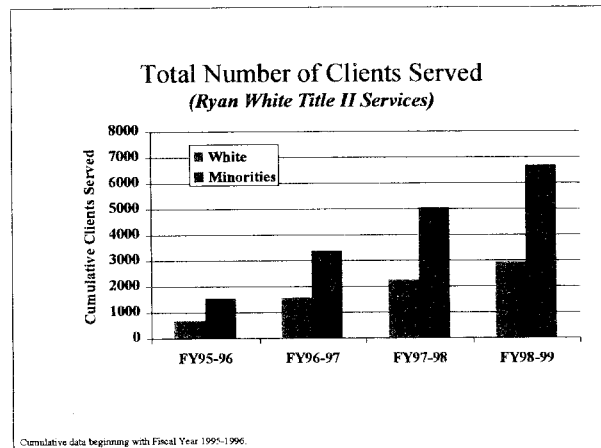


From 1993 to 1995, the ADAP program served an average of 536 new clients each year.

From 1996 to 1998, the ADAP program served an average of 731 new clients each year.

For 1999, the ADAP program served 864 new clients bringing the total number of clients served to 5611.



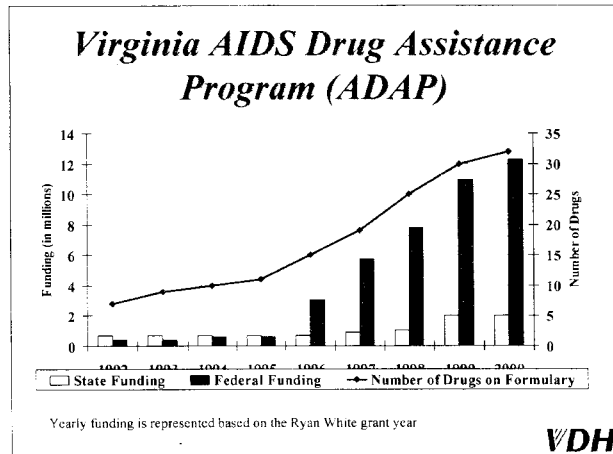


	<u>White</u>	<u>Minorities</u>
<u>FY95-96</u>	693	1515
<u>FY96-97</u>	1580	3324
<u>FY97-98</u>	2259	4937
<u>FY98-99</u>	2933	6565

In FY95-96 minorities accounted for 68% of all clients served. Cumulatively, the percentage of minorities served increased to 69% in FY98-99.

Minorities include African Americans, Hispanics, Asians and American Indians. Unknown races are excluded.





Since 1992, the number of drugs on the ADAP formulary has more than quadrupled from 7 to 32. New drugs are continually added to the formulary throughout the year.

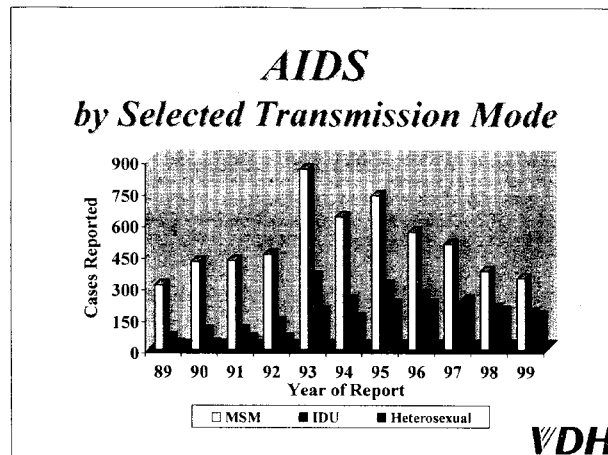
Since 1996, Federal funding for ADAP has quadrupled from a little over \$3 million to over \$12 million for grant year 2000.



<b>Ryan White Title II Funding</b> <b>Total Federal Award vs. Total State Match, 1994-2001</b>		
<u>GRANT YEAR</u>	<u>STATE</u>	<u>FEDERAL</u>
1994	1,227,899	2,455,797
1995	1,422,398	2,844,796
1996	2,770,488	5,540,975
1997	4,162,942	8,325,883
1998	5,226,121	10,452,242
1999	6,549,646	13,099,292
2000	7,422,598	14,845,195
2001	7,922,598*	15,845,195*
* Projected		

The state is required to match federal funds on a 1:2 ratio (1 state dollar for every 2 federal dollars)





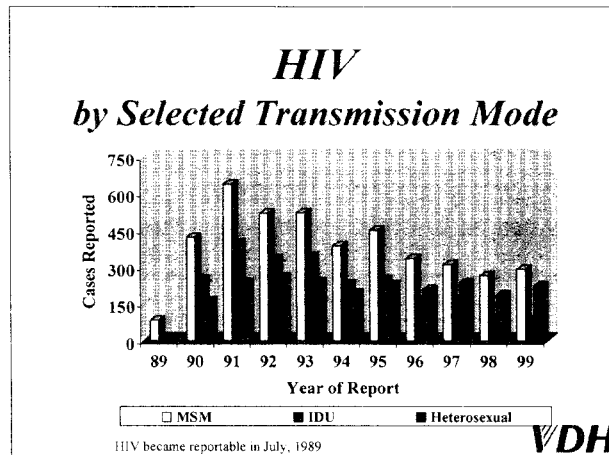
Although the percentage of MSM transmission of reported AIDS cases has declined in recent years, MSM is still the leading mode of transmission.

Since 1995, MSM and IDU transmissions have continually declined. Heterosexual transmission has declined since 1997.

In 1995 MSM transmission accounted for 50% of total AIDS cases reported (IDU - 21%, Heterosexual - 15%).

In 1999, the proportions of reported AIDS cases have changed to MSM - 37%, IDU - 19% and Heterosexual - 18%.

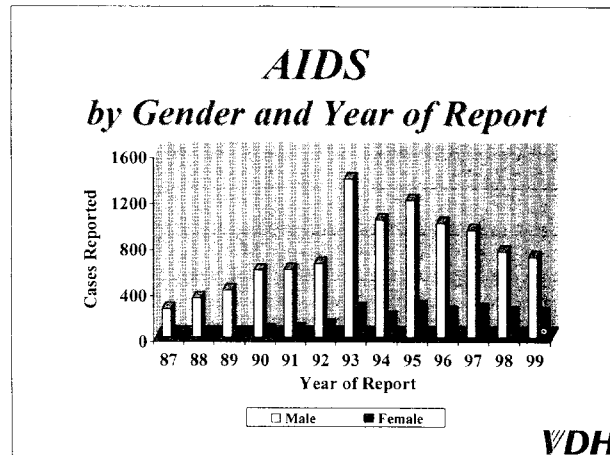




Although the percentage of MSM transmission of reported HIV cases has declined in recent years, MSM is still the leading mode of transmission.

In 1996, heterosexual transmission of HIV became the second leading mode of HIV transmission due primarily to a decrease in reported IDU cases. The number of reported heterosexual transmission cases has remained relatively constant since 1991, although its percentage of total cases has increased.





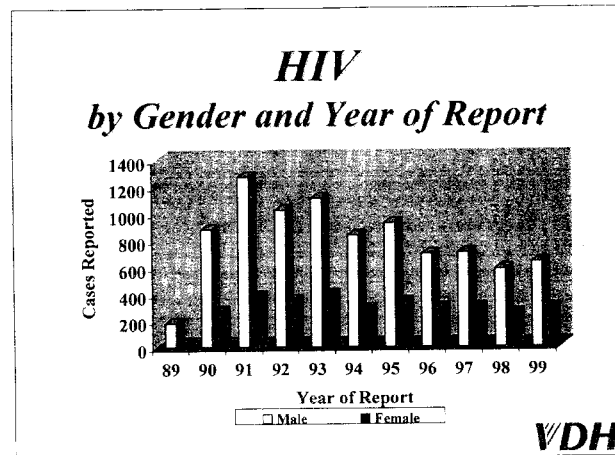
The percentage of reported AIDS cases among females has steadily increased since reporting began. Since 1993, this percent increase has been primarily due to a decrease in the number of males reported with AIDS.

In the late 1980s, females accounted for 8-10% of all cases.

By 1993, females accounted for 15% of all cases.

In 1999, females made up 23% of all AIDS cases.



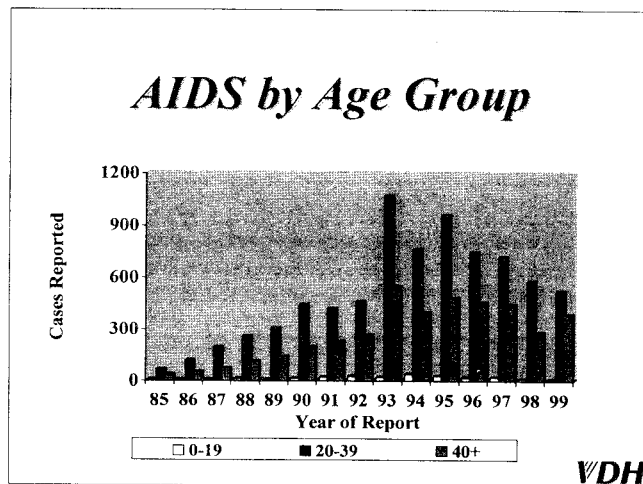


Reported female HIV cases indicate a similar pattern as AIDS cases in that the number of reported female cases has remained somewhat stable while reported male cases continues a more noticeable decline.

In 1991, females accounted for 23% of all cases.

In 1999, females made up 31% of all reported HIV cases.



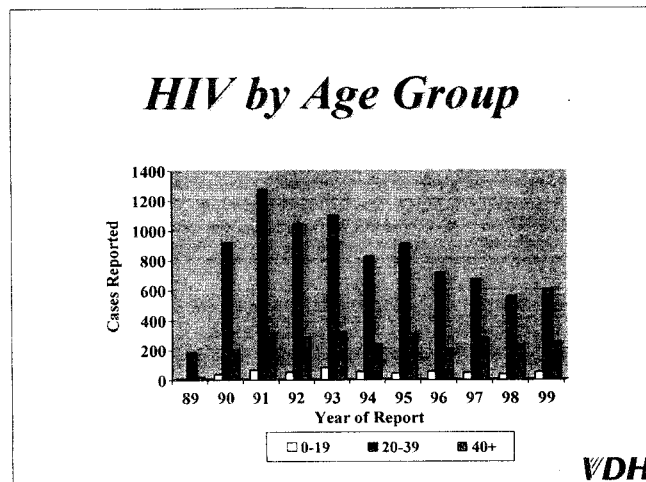


Virginians aged 20-39 have consistently accounted for the largest proportion of reported AIDS cases.

Data for 1999 indicate 20-39 year olds make up 57% of all reported AIDS cases.

Cumulative data suggests that Virginians aged 40+ are continuing to make up a larger percent of total reported AIDS cases (1989 - 31%, 1995 - 33%, 1999 - 42%).





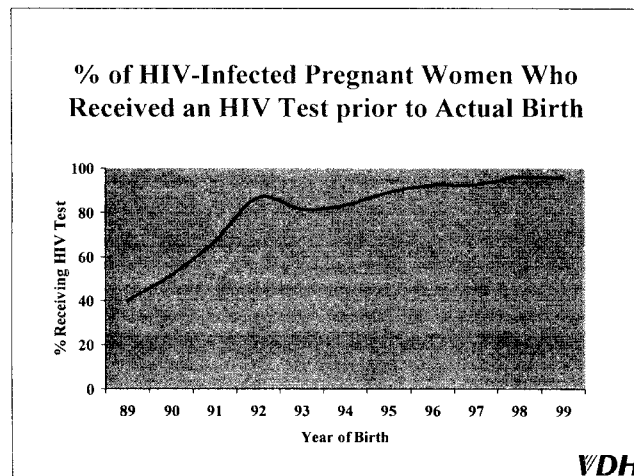
Virginians aged 20-39 have consistently accounted for the largest proportion of reported HIV cases; however, the number of reported cases has generally declined since 1995.

Cumulatively, 30-39 year olds make up the largest percent of HIV cases among all males (41%). 20-29 year olds make up the largest percent of HIV cases among females (38%).

Data for 1999 indicates 20-39 year olds make up 66% of all HIV cases for the year.

Cumulative data suggests that Virginians aged 40+ are continuing to make up a larger percent of HIV cases (1989 - 8%, 1995 - 24%, 1999 - 29%).



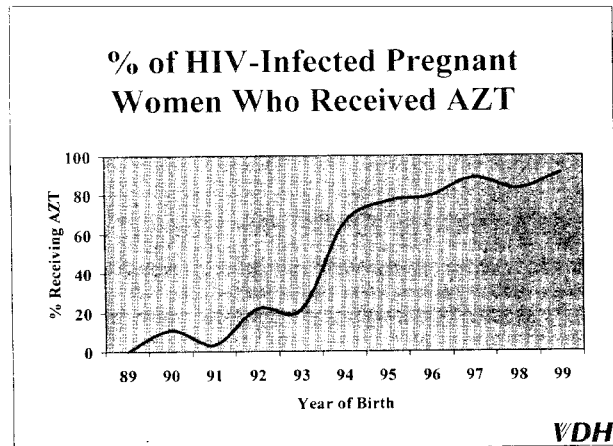


In 1995, Virginia passed legislation requiring all physicians to require HIV counseling, offer HIV testing and encourage use of AZT to pregnant women.

The percentage of HIV+ pregnant women who received an HIV test prior to actual birth increased from 40% in 1989 to 96% in 1999.

In 1999, 22 HIV+ pregnant women were reported and 4 HIV+ perinatally exposed pediatric cases were reported.

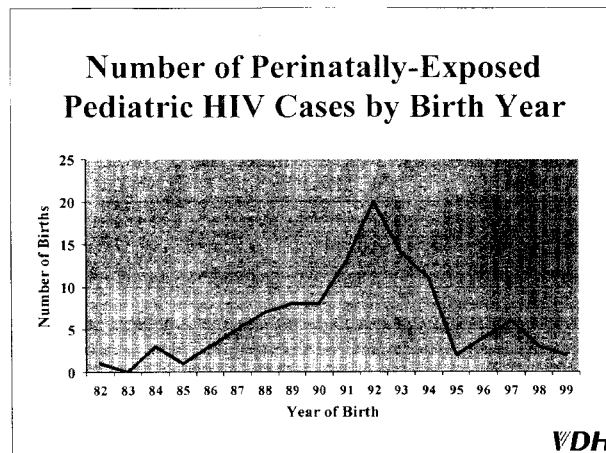




In 1994, CDC issued recommendations for AZT use with HIV+ pregnant women.

Since 1993, the percentage of HIV+ pregnant women who received AZT at some point has increased from 21% to 67% in 1994 to 91% in 1999.





The number of perinatally exposed pediatric HIV cases born in a given year peaked in 1992 with 20 cases.

The number of perinatally exposed pediatric HIV cases decreased from 20 cases in 1992 to 11 cases in 1994.

In 1995, VA legislation took effect requiring physicians to offer HIV testing, only 2 cases were reported. 4 cases were reported in 1996, 6 cases were reported in 1997, and 3 cases were reported as having been born in 1998.

2 cases were reported as having been born in 1999.



Mr. BILIRAKIS. Thank you very much, Dr. Peterson.

Dr. John Harley, M.D., Ph.D., is a member and program head of the Oklahoma Medical Research Foundation out of Oklahoma City. Welcome, Dr. Harley, and please proceed, sir.

**STATEMENT OF JOHN B. HARLEY, OKLAHOMA MEDICAL  
RESEARCH FOUNDATION**

Mr. HARLEY. Thank you, Mr. Chairman and ranking member, and committee members.

I have two initiatives that I'll mention that are going on in my laboratory. First is the Lupus Multiplex Registry and Repository, as a national collection of pedigrees with multiple members of lupus. We facilitate the work of many scientists by providing them with data and materials from these families. And second, I act as principal investigator on a study of genetic linkage of lupus in African Americans. We understand this is the only study funded by the NIH that specifically concentrates on genetic linkage in African Americans.

The OMRF was chartered in 1946 as a private, non-profit biomedical research institution which employs over 400 scientists, physicians, technicians and administrative support personnel. The OMRF focuses on several critical areas of research, cancer, heart disease, diabetes, Alzheimer's and Parkinson's disease, as well as lupus and other autoimmune diseases. I am pleased to discuss a subject that's vital to Oklahoma, the Health Care Fairness Act, H.R. 3250, because Oklahoma, which means land of the red man in Choctaw language, is home to 263,000 Native Americans, the second highest number of Native Americans of any State in the U.S.

We have instituted a biomedical research center unique to Oklahoma, the Native American Biomedical Research Center. This center will address many of the same issues the Health Care Fairness Act addresses, including the dramatic disparity in the incidence of many diseases in our Native American population.

Oklahoma is blessed with the rich and ancient traditions that spring from our Native American heritage. In fact, we not only have one of the largest populations of Native Americans in the country, but also among the most diverse, with over 100 separate tribal groups represented. Unfortunately, we also have particularly serious problems from the numerous and severe medical conditions that affect this population.

For example, it is especially true that the high incidence of autoimmune diseases in Native Americans, these are diseases where the immune system turns on itself and attacks one's own body, diseases and disorders thought to have an autoimmune origin include rheumatoid arthritis, lupus, type 1 diabetes or juvenile diabetes, multiple sclerosis, scleroderma and others. In some groups of Native Americans, these diseases are especially common.

There is great scientific interest at the present time in the genetics of autoimmune diseases, in spite of the fact that research in this area is one of the most traditionally underfunded in the U.S. Oklahoma's medical investigators have special opportunities to contribute to the solution of these seemingly overwhelming problems through research and genetics. Indeed, scientists at OMRF have



done some of the most significant work in the field of autoimmunity and appreciate the opportunity for discovery and helping solve the serious problems that these disease pose in selected groups of Native Americans.

In my personal experience in the rheumatic disease clinic in one of the State's Indian Health Service hospitals, the spectrum of autoimmune diseases and their clinical presentations are very different in Native Americans compared to what we know from Americans of European extraction. I am concerned that the very definitions of what the diseases are must be changed to accommodate how differently they find expression in Native Americans. Accordingly, this also implies that different therapeutic management is likely to be warranted among the affected Native Americans.

Autoimmune diseases affect different populations in different ways. In Native Americans, for example, rheumatoid arthritis is found in as many as 7 percent of some groups, which is more than five times more frequent than that found in European Americans. Lupus is another example of high incidence of autoimmune diseases in certain Native American populations.

In the Oklahoma Sioux, lupus appears to have an incidence of about fivefold greater than that found in European Americans. Other smaller groups, such as the Apache Tribe, also have a dramatically high incidence.

Working on the genetic problems of Native Americans has a number of advantages. First, the gene pool is different from that found in European Americans or in African Americans. There are also, of course, major differences between Native American groups. Second, Native Americans offer the opportunity to apply newer genetic approaches using an isolated population strategy or genetic add mixture. These approaches have a much greater prospect of success than do the much larger and more expansive studies performed in the out-bred American population.

For example, scleroderma is found at a rate of about 1 in 200 of the Oklahoma Choctaw, about 50 times the rate found in both non-Choctaw Native Americans in Oklahoma and in European Americans. One of these new genetic approaches was used to identify two regions of the human genome which contains genes that appear to dramatically increase the risk of scleroderma in the Oklahoma Choctaw.

The advances in scientific technology have been revolutionary in the area of genetics. This technology is being joined with the research excellence of numerous biomedical sciences at the OMRF, University of Oklahoma Health Sciences Center and other research facilities in the State to address in a major way the genetics of autoimmune disease in our Native American populations. Our opportunities, then, are not only to advance medical knowledge, but also to help provide a solution to these serious, life-long, often debilitating diseases in particularly affected tribal groups.

The Oklahoma Medical Research Foundation proposes to build a unique genetic unit focusing upon disease processes in Native Americans with an initial and special emphasis on autoimmune disorders. We propose to bring together all the necessary ingredients that will result in important progress and contribute to solv-



ing these problems for affected Native Americans in Oklahoma as well as for all of mankind.

An NIH center for research on minority health would facilitate funding of OMRF's Native American Research Center. In addition, the new NIH center would accelerate studies into dramatic disparities among incidence of many diseases among all of our minority peoples. Medical breakthroughs and scientific advances that originate from studies focusing on minority populations would likely be very beneficial to all Americans. OMRF's mission statement is that more may live longer, healthier lives. With an NIH center focus on minority health, we can better do our best to ensure that OMRF's goals of longer, healthier lives are achieved for all.

[The prepared statement of John B. Harley follows:]

PREPARED STATEMENT OF JOHN B. HARLEY, PROGRAM HEAD, ARTHRITIS AND IMMUNOLOGY, OKLAHOMA MEDICAL RESEARCH FOUNDATION

Thank you for the opportunity to speak with the subcommittee. My name is Dr. John Harley and I am the Head of the Arthritis and Immunology Program at the Oklahoma Medical Research Foundation (OMRF). Chartered in 1946, OMRF is a private, non-profit biomedical research institution which employs over 400 scientists, physicians, technicians, and administrative and support personnel. OMRF focuses on several critical areas of research: Cancer, heart disease, diabetes, Alzheimer's and Parkinson's diseases, as well as lupus and other autoimmune diseases.

Today, I am honored to discuss a subject that is vital to Oklahoma, the Health Care Fairness Act. Because Oklahoma is home to 263,000 Native Americans, the second highest number of Native Americans in any state in the U.S., we have instituted a biomedical research center unique to Oklahoma—the Native American Biomedical Research Center. This Center will address many of the same issues that the Health Care Fairness Act addresses, including the dramatic disparity in the incidences of many diseases in our Native American population.

Oklahoma is blessed with the ancient and rich traditions that spring from our Native American heritage; in fact, our state has one of the largest populations of Native Americans in the country. Unfortunately, we also have particularly serious problems from the numerous and severe medical conditions that affect this population. This is especially true in the high incidence of autoimmune diseases—where the immune system “turns on itself” and attacks one's own body—among the more than 100 separate tribal groups in Oklahoma. Diseases and disorders thought to have an autoimmune origin include rheumatoid arthritis, lupus, diabetes (Type 1, or “juvenile”), multiple sclerosis, scleroderma and others. In some groups of Native Americans, these diseases are especially common.

There is great scientific interest at the present time in the genetics of autoimmune diseases, in spite of the fact that research in this area is one of the most underfunded in the U.S. Oklahoma's medical researchers have special opportunities to contribute to the solution of these seemingly overwhelming problems through research in genetics. Indeed, scientists at OMRF have done some of the most significant work in the field of autoimmunity and appreciate the opportunity for discovery and for helping solve the serious problems that these diseases pose in selected groups of Native Americans. Indeed, in my personal experience the spectrum of autoimmune diseases and their clinical presentations are so different than what is seen in Americans of European extraction, that I am suspicious that different methods of description and, possibly, therapeutic management may be warranted among Native Americans.

Autoimmune diseases affect different populations in different ways. In Native Americans, for example:

- Rheumatoid arthritis is found in as many as 7% of some groups, which is more than five times more frequent than in European-Americans. Lupus is another example of the high incidence of autoimmune diseases in certain Native American populations.
- In the Oklahoma Sioux, lupus appears to have an incidence of about five-fold greater than that found in European-Americans.

Working on the genetic problems in Native Americans has a number of advantages. First, the gene “pool” is different from that found in European-Americans or African-Americans. There are also, of course, major differences between Native American groups. Second, Native Americans offer the opportunity to apply newer



genetic approaches using “admixture,” a method of determining racial mix between ethnic groups and isolated populations which cannot be applied with the same expectation of success in the “outbred” American population. For example, scleroderma is found at a rate of about one in 200 among the Oklahoma Choctaw, about 50 times the rate found in both non-Choctaw Native Americans in Oklahoma and European-Americans. One of these new genetic approaches was used to identify two regions of the human genome, which appear to dramatically increase the risk of scleroderma in the Oklahoma Choctaw.

The advances in scientific technology have been revolutionary in the area of genetics. This technology is being joined with the research excellence of numerous biomedical scientists at OMRF, the University of Oklahoma Health Sciences Center, and at other research facilities in the state to address in a major way the genetics of autoimmune disease in our Native American populations. Our opportunities, then, are not only to advance medical knowledge but also to help provide a solution to these serious, lifelong, often debilitating and sometimes fatal diseases in particularly affected tribal groups.

The Oklahoma Medical Research Foundation proposes to build a unique genetic unit focusing upon disease processes in Native Americans, with an initial and special emphasis on autoimmune disorders. We propose to bring together all the necessary ingredients that will result in important progress and contribute to solving these problems for affected Native Americans in Oklahoma, as well as for all of mankind.

An NIH Center for Research on Minority Health would facilitate funding of OMRF's Native American Research Center. Additionally, the new NIH Center would accelerate studies into the dramatic disparities among the incident of many diseases among all our minority peoples.

Medical breakthroughs and scientific advances that originate from studies focusing on minority populations will likely be very beneficial to all Americans. OMRF's mission statement is “. . . that more can live longer, healthier lives.” With a NIH center focusing on minority health, we can better do our best to ensure that OMRF's goals of longer, healthier lives are achieved for all.

Mr. BILIRAKIS. Thank you, Doctor.

Dr. Elena Rios is President of the National Hispanic Medical Association, located here in Washington, DC. Doctor, please proceed.

#### **STATEMENT OF ELENA RIOS, PRESIDENT, NATIONAL HISPANIC MEDICAL ASSOCIATION**

Ms. RIOS. Thank you, Congressman and guests. I am deeply honored to join you today in support of the Health Care Fairness Act, H.R. 3250, which has the strong potential to create knowledge and innovation. Medical and health services research, cultural competence training for health professions and civil rights monitoring, which I believe will tremendously decrease the disparities that face all the minorities represented today in the United States.

I'm representing two critical national Washington, DC based organizations, the National Hispanic Medical Association, which represents 30,000 licensed Hispanic physicians in the United States, and the Hispanic Serving Health Professions Schools, Inc., which was established in 1996 by the Department of Health and Human Services in response to the White House's Educational Excellence for Hispanic Education Initiative, which represents 20 medical schools from across the United States, with 9 percent Hispanic student enrollment.

We also work closely with the Hispanic Health Coalition, which represents 30 national organizations. I'm here today to urge you to take up the challenge to pass H.R. 3250 and make America healthier.

During my brief presentation, I just want to focus on three issues: the current health status of Hispanics, the need for research and cultural competence in medical services for Hispanics and all



Americans, and to provide you with our recommendations to improve the bill. In terms of the Hispanic health status, let me just start by saying that Hispanics really are the largest population in the United States right now, the current U.S. census estimates of 30 million do not include the 4 million from Puerto Rico or the 3.5 million that the INS estimates as current residents from Hispanic backgrounds. I know by the year 2050 the projections say that 1 in every 4 Americans will be Hispanic. Indeed, the United States is soon to become the second largest Spanish speaking country in the world.

Hispanics are a heterogenous group from 20 countries. There's a lot of different cultures to deal with, even among the Hispanics. The socioeconomic factors, as we know, determine the lifestyle of people in this country, and Hispanics are one of three, below the poverty level. The median income of \$23,000 versus the \$41,000 for non-Hispanic whites. In 1998, Hispanics continued to have the lowest educational attainment, with Mexican Americans having 50 percent high school dropouts.

In terms of access to health care, Hispanics have very, very poor socioeconomic status and very poor access to health care. The numbers of uninsured in the United States has increased to 44 million and are increasing at a faster rate as we heard earlier, due to a myriad of factors. But Hispanics are the largest group of uninsured in the United States, 2 out of 5 Hispanics, according to a recent commonwealth fund, introduced data at our National Hispanic Medical Association annual conference, and there will be more work in this area as several different organizations look at strategies to eliminate this disparity in the insurance rates of Hispanics.

Hispanics are also the least likely to be linked to regular sources of care, as we heard earlier.

What I'd like to just focus on now is the need for medical research. We heard a lot about this earlier, but I think in order to understand the disease pattern that affects Hispanics, factors that lead to decreasing barriers for Hispanics to access care, factors that increase outreach to Hispanics for health promotion programs and treatment services and physical and mental health and research programs that can train Hispanic health profession students to become researchers, we critically need to increase biomedical and health services research that targets all the major population groups fairly and equitably. This bill should promote support for research, not only in biomedical institutions, but by community based agencies and non-profit entities that target all the minority communities in the country.

There has been minimal Federal support for Hispanics to be included in research, and we urge you to encourage research with passage of this bill.

In terms of the need for cultural competence curriculum, cultural competence has been defined as a set of academic and interpersonal skills that allow individuals to increase their understanding and appreciation of cultural differences and similarities within, among and between groups. This requires a willingness and an ability to draw on community based values, traditions and customs and to work with knowledgeable persons of and from the com-



munity in developing focused interventions, communications, and other supports.

There is an urgent need to adopt legislation like H.R. 3250 that promotes health professions cultural competence curriculum, given the growing diversity in the United States population. We believe that successful strategies for increasing access to health insurance include cultural competence standards for health professions education, as well as for the whole health system, the facilities, the standard services, language services, etc.

There is definitely a critical need for cultural competence training for the future health work force of the country, as well as the current work force to eliminate health disparities, as we heard earlier.

We believe there are important principles that enhance the cultural competence of the physician in the physician patient relationship, including respect for values, respect for health and illness beliefs, respect for family dynamics and decisionmaking, cultural awareness, assimilation, acculturation levels, role of traditional healers, role of the pharmacists in our community, Spanish, using the language Spanish, elimination of biases, awareness of Hispanic sub-groups, nuances, languages and diet. We believe that more patients from the Hispanic community and other ethnic communities would access services if they were provided in a culturally competent manner.

In terms of recommendations, for research we just really thought that the research endowment program is only one program that could be developed by this bill. Another important aspect is actual development of consortia among biomedical institutions and partnerships development with community based organizations and health professional organizations to enhance minority research.

In terms of the centers of excellence for research training, we just thought it was important to commend the bill for having the Health Resources and Services Administration centers of excellence mentioned. But these are separate from the new NIH centers of excellence which wish to be created.

Mr. BILIRAKIS. Doctor, please summarize.

Ms. RIOS. In terms of the cultural competence curriculum, as I said earlier, we really should understand the importance of the Hispanic physicians and other physicians from our communities and being able to share their expertise in developing curriculum for developing a center for cultural and linguistic competence in health care that could coordinate all the curriculum mentioned in the bill.

In summary, I'd just like to say that we commend the efforts of the Committee and we look forward to working with you all in developing more of the bill.

Thank you.

[The prepared statement of Elena Rios follows:]

PREPARED STATEMENT OF ELENA RIOS, DIRECTOR, HISPANIC-SERVING HEALTH PROFESSIONS SCHOOLS, INC., PRESIDENT, NATIONAL HISPANIC MEDICAL ASSOCIATION

#### INTRODUCTION

Honorable Congressmen and Congresswomen and guests, I am deeply honored to join you today in support of the Health Care Fairness Act, H.R. 3250 which has the strong potential to create knowledge and innovation—medical and health services research, cultural competence training for health professions, and civil rights moni-



toring—which I believe will tremendously decrease the disparities in health that face Hispanics, African Americans, Asian Americans/Pacific Islanders, and Native Americans in the United States today.

I am representing two critical national Washington DC based organizations: a) National Hispanic Medical Association, which represents 30,000 licensed Hispanic physicians in the United States; and b) Hispanic-Serving Health Professions Schools, Inc., (established in 1996 by the Department of Health and Human Services in response to the White House Educational Excellence for Hispanic Americans Initiative), which represents 20 medical schools from across the nation with 9% Hispanic student enrollment. The missions of both organizations are to improve the health of Hispanics. We work closely with the Hispanic Health Coalition, representing 30 national and local organizations, and with minority coalitions to continue to challenge policy-makers to address the economic, social, environmental and cultural factors responsible for the poor health status and the poor access and utilization of health and mental health services of our communities. I am here today to urge you to take up the challenge to pass HR 3250 and make America healthier.

During my brief presentation, I will focus on three major issues—1) the current health status of the Hispanic population in the United States, 2) the need for research and cultural competence in medical services for Hispanics and all Americans, and 3) to provide you with our recommendations to improve the Health Care Fairness Act, H.R. 3250.

#### HISPANIC HEALTH STATUS

##### *Population Growth, Poor Health and Access to Care*

The Hispanic population has become the largest minority group in the United States. According to the U.S. Census estimate for 1999, there are 32 million Hispanics or nearly 12% of the population. If you include the Immigration and Naturalization Service estimates of Hispanic residents who lack legal status (3.5 million) and the Puerto Rico Commonwealth population (4 million), the Hispanic population in 2000 numbers about 40 million. By the year 2050, 1 in every 4 Americans will be Hispanic. Indeed, the U.S. is soon to become the second largest Spanish speaking country in the world, second to Mexico.

Hispanics are a heterogeneous group representing more than 20 countries. The 1999 population statistics released by the U.S. Census reported that Hispanic's county of origin were 66% Mexico, 14% Central/South America, 10% Puerto Rico, 7% Caribbean and other countries, and 4% Cuba.

Nearly 87% of all Hispanics live in ten states: California, Texas, New York, Florida, Illinois, New Jersey, Arizona, New Mexico, Colorado, and Nevada. Major Hispanic metropolitan areas include: Los Angeles-Orange-San Bernardino Counties, California; New York-Northern New Jersey-Long Island-Connecticut, New York; Miami-Fort Lauderdale, Florida; Chicago-Gary-Lake County, Illinois, Indiana, Wisconsin; San Francisco-Oakland-San Jose, California; Houston-Galveston-Brazoria, Texas; Dallas-Fort Worth, Texas; and San Antonio, Texas.

The following areas were home to 58% of Hispanics in 1994:

- Los Angeles County—nearly 7 million or 1 in 4 persons
- New York—nearly 3 million
- San Francisco, Miami, Chicago—nearly 1 million
- Houston and Dallas—800,000
- San Antonio—600,000

In 1994, the Census estimated that 39% of Latinos were born outside of U.S. Median Age = 26 years old, 10 years younger than non-Hispanic whites

Socioeconomic factors determine the lifestyle of people in the U.S. One out of three Hispanics in 1998 were below the Federal poverty level. The 1993 median income was \$23,700 for Hispanics vs. \$41,100 for non-Hispanic whites. In 1998, Hispanics continued to have the lowest education levels of attainment with 54.7% having attained high school graduation and 10% BA degrees. For Mexican Americans, 50% of those 25 years old and above have 8 years of education or less.

Hispanics and Disease Mortality Rates (age adjusted, in order of frequency): Heart Disease; Cancer; Unintentional Injuries; Cerebrovascular Disease; Diabetes; and HIV/AIDS

Immigrant health issues are very important for the Hispanic community, since the majority of immigrants to the U.S. are from Mexico. There continues to be an emphasis on issues of access to health care services with Spanish language translators and information and restoring benefits such as food stamps that impact on health.

Spanish language use is a major factor for communicating with Hispanics in the U.S. 68% are monolingual in Spanish, 86% of Hispanics report Spanish as their first language, 64% feel more comfortable with Spanish, and 69% report Spanish spoken



at home. It is no wonder that Spanish media that has loyal viewers, listeners, and readers, including TV and radio and newspapers have been extremely successful in the U.S.

To add to the poor socioeconomic status of the Hispanic population, in general, they do not have adequate access to the health care delivery system. The numbers of uninsured in the United States has increased to 44 million and are increasing at a faster rate due to a myriad of factors. Hispanics are the largest group of uninsured in the United States. 2 out of 5 Hispanics are uninsured according to a February 2000 Commonwealth Fund Report, introduced at the National Hispanic Medical Association Annual Conference, the so called "working poor." The lack of health insurance coverage varies depending if they are children or adults, if they are poor, if they work in the service or farming industries, or if they are immigrants or undocumented workers.

Hispanics are least likely to be linked to a regular source of care. Over 30% do not have a family doctor, or clinic to go when they need care and the Hispanics, 25 years and older, have the least number of dental visits compared to Whites or Blacks. For children, Hispanics had the highest rates without a physician visit in the past year and Hispanics had 3 times the rate of Whites and 2 times the rate of Blacks for no regular source of care. Most non-citizens who have become legal residents since 1996 are barred from Medicaid for five years, regardless of need.

This situation is more severe among Spanish-speaking populations due to the shortage of bilingual and bi-cultural physicians and other health and mental health professionals. The United States medical schools have been able to produce only about 5% Hispanic physicians and with the demise of affirmative action, we recognize the worsening numbers of underrepresented minority medical students. Furthermore, due to health care providers' lack of familiarity with the culture and language of patients, and with the limited medical education about cultural competence, Hispanics do not receive the state-of-the-art treatment that the American health care system is so proud to provide. With the trend toward managed-care systems of care the access and the quality of medical care has become worse for Hispanics and is expected to become even more disastrous.

Other major factors that need to be addressed to improve access to health care in this country include:

- Health Care Facilities (hospitals, clinics, private medical offices)
- Transportation
- Child Care
- Language Services Access

Hispanics have one of the worst health status in this country. To begin with, diabetes type 2 is three times higher among Hispanics, compared to non-Hispanics; cervical cancer is the highest among Hispanic women (followed by Vietnamese women); mortality for breast cancer is one of the highest among Hispanic and African American women due to the fact that minority women do not have access to health care for early cancer prevention and screening, and they come at a later stage for diagnosis and treatment; prostate cancer is killing our men, and due to the heavy marketing of the tobacco and alcohol industries, lung cancer (due to smoking) and alcoholism are very serious health problems in our community; HIV/AIDS and other sexually transmitted diseases, combined with tuberculosis, continue to be devastating for the health of our youth and adults. For example, HIV is the third cause of death among Hispanics, in the U.S., and Puerto Rico has the second highest HIV rate in the country. Furthermore, Hispanics tend to live in neighborhoods with high environmental pollution; exposed to violence in the street, in their homes and in their workplace; and they are most likely to work in occupations where they are exposed to dangerous chemicals (e.g., pesticides) and poor working conditions. This is particularly true among janitors, landscapers, agricultural workers, etc. I could go on and on documenting the seriousness of our problems. However, it is important for policy-makers like yourselves to keep in mind that the health status of Hispanics vary by age, nationality, gender, socioeconomic status, immigration status and by levels of acculturation and assimilation to the mainstream society.

#### *Need for Better Medical Research about Hispanics*

We know that medical and health services research can lead to information that will improve the health of our nation.

In order to better understand the disease patterns that affect Hispanics, factors that lead to decreasing barriers for Hispanics to access to care, and factors that can increase outreach to Hispanics for health promotion programs and treatment services in physical and mental health, and research programs that can train Hispanic health professions students to become researchers, we critically need to increase biomedical and health services research that targets all the major population groups



fairly and equitably. This bill should promote support for research by biomedical institutions, community based agencies, non-profit entities that target all minority communities in the U.S. There has been minimal Federal support for Hispanics to be included in medical and health services research, and we urge you to encourage increased Hispanic research and Hispanics entering research careers with this bill.

One of the most serious problems impacting the health of Hispanics is the lack of data on their health and medical needs and the lack of biomedical research on the diseases with the greatest prevalence in this population. Until 1990, we did not even know how many Hispanics die in this country or the mortality rates of certain diseases. As a member of the National CDC HIV Strategic Planning Committee and the Medicare Education Advisory Committee, we find that we can not develop many measurable objectives for Hispanics because the data is not available. This situation is more severe at the local level where departments of healths in smaller communities do not have the infrastructures to collect data. Some states, especially in the South, with recent great influxes of Mexican immigrants have databases that only recognize Black, White and Other.

Another very important research finding has been the disparities in health, including access, utilization of health services, health status, medical treatment and disease patterns for minorities. A recent report on the from the Agency for Health Care Research and Quality found that Hispanics were more likely than whites to be in fair or poor perceived health status but less likely to be reported as having functional limitations. Indeed, the DHHS has challenged the U.S. to develop partnerships for outreach and research through its Racial and Ethnic Disparities in Health Initiative.

A major focus of the Department of Health and Human Services "Hispanic Agenda for Health" and the Health Care Fairness Act is to meet the challenge of little research on Hispanics. DHHS, through this initiative established the Hispanic-Serving Health Professions Schools, Inc., in response to President Clinton's Executive Order 12900, "Educational Excellence for Hispanic Americans" to develop comprehensive, coordinated faculty development Fellowships to increase research on Hispanic health at member institutions—20 medical schools. In the future, HSHPS plans to expand to public health schools, nursing schools, dental schools and other health professional schools. HSHPS has developed collaborative efforts for the first time among medical schools to develop Hispanic research and Hispanic health researchers. HSHPS also represents all the HRSA Centers of Excellence. We urge your support that can continue these efforts.

The National Hispanic Medical Association has also encouraged research careers at our national conference, and has developed a Research Network to identify physicians who are Hispanic researchers and to encourage grant applications to the Federal government. NHMA physicians have a tremendous base of patients who are Hispanic for research in our community that could prove valuable for efforts to eliminate disparities in health in our country. We urge you to support the research efforts of other Hispanic organizations with expertise in working with the Hispanic community.

#### *Need for Health Professions Cultural Competence Curriculum*

Cultural competence has been defined as a set of academic and interpersonal skills that allow individuals to increase their understanding and appreciation of cultural differences and similarities within, among, and between groups. This requires a willingness and ability to draw on community-based values, traditions, and customs and to work with knowledgeable persons of and from the community in developing focused interventions, communications and other supports.

There is an urgent need to adopt legislation that promotes health professions cultural competence curriculum, given the growing diversity in the U.S. population and especially, given the tremendous increase in Hispanics across the nation, and given the critical levels of uninsured Hispanics.

We believe that successful strategies for increasing access to health insurance must include cultural competence standards for health professions education as well as for the health system facilities and services and standards for language services.

There is a critical need for cultural competence training for the future health workforce and the current workforce to eliminate the health disparities for Hispanics and others with cultural backgrounds, to increase quality care, to decrease the likelihood of liability/malpractice claims, and to encourage utilization to services. By supporting this legislation, we can support all these outcomes which will decrease costs and improve the health of the nation.

We find that once Hispanics enter the medical care system, they find that the health care system in this country is not user friendly, it has no capacity to deal with populations who have different cultural backgrounds or different illnesses; and



that classicism, racism and social discrimination impact negatively the quality of the services provided. On the other hand, the literature shows that, in general, Hispanic physicians provide services to a predominant Hispanic clientele. There is a growing demand for Hispanic physicians. Why is this?

We believe that there are important principles that enhance the cultural competence of the physician in a physician-patient relationship: respect for values, health and illness beliefs, respect for family dynamics and decision-making, cultural awareness, assimilation and acculturation levels and health behaviors, role of traditional healers, role of pharmacists, Spanish use, elimination of biases, awareness of Hispanic sub-group nuances, language, and diet. We believe that more patients from the Hispanic community and other ethnic communities would access services if they were provided in a culturally competent manner.

The NHMA and HSHPS are dedicated to sharing our expertise of Hispanic physicians who have served numerous Hispanic patients and their families with the development of curriculum for future generations of health professionals. We all benefit by this bill that provides support for the collection of this unique knowledge and the development of formal training programs in medical schools, nursing schools, public health schools, dental schools, mental health professional training programs, etc.

There has been an acceptance of cultural competence over the past decade by the Federal government, state governments, undergraduate and graduate medical education, nursing education and mental health education focused on service delivery and curriculum development for health professions and health staff in public clinics. The following are important milestones:

- 1992—State of California Cultural Competency Task Force for Medicaid
- 1995—U.S. Department of Health and Human Services Office on Women's Health and Office of Minority Health National Conference on Cultural Competence and Women's Health Medical Education Curricula; Curricula Collection Distributed
- 1996—DHHS Hispanic Agenda for Action establishes a Cultural Competence Workgroup
- to stimulate activities across the Department
- 1997—Substance Abuse and Mental Health Services Administration develops Cultural Competence Principles for Mental Health and Substance Abuse Treatment
- 1998—Council on Graduate Medical Education Minority Workforce Report
- 1998—DHHS OWH and OMH Review of the United States Medical Licensing Examination for Cultural Competence
- 1998—Health Care Financing Administration Regulations on Cultural Competence for all Medicaid and Medicare contractors published
- 1999—Liaison Committee on Medical Education Standard on Cultural Competence Approved (accreditation for all medical schools)
- 2000—Accreditation Council for Graduate Medical Education Standard for Cultural Competence in process (accreditation for residency programs)
- 2000—OMH publishes Recommendations for Standards for Culturally and Linguistically Appropriate Health Services for Public Comment

In addition, over the past decade, private sector organizations including HMOs, pharmaceutical companies, hospitals, and national health professions organizations have sponsored conferences and training programs for staff in order to develop cultural competence for more effective medical delivery for Hispanic and other ethnic groups in their target areas.

Centers of Excellence—statement about their importance to Hispanic health

HSHPS same type of statement—need for coordinating programs under this legislation

NHMA—cultural competence projects

#### *Recommendations to Improve HR 3250*

**1. Research**—The \$100 million appropriation for minority research should be distributed to research efforts focused on all four of the major minority groups—Hispanic, African American Asian American and Pacific Islander and Native American. There should be a fair and equitable distribution plan.

The research endowment program is only one program mentioned in the bill. The Hispanic-Serving Health Professions Schools, Inc. conducts the HSHPS Research Fellowship Program to develop faculty for its 20 member medical schools. Some research funding in this bill could be used to develop faculty through fellowships, who would become leaders in the health arena for Hispanic research.

Another important aspect for minority research is consortium development among biomedical institutions and partnership development with community based agencies and health professional associations to enhance minority research. In the case of Hispanics, we could better understand regional and sub-group variations related



to disease pathophysiology, medical treatment issues if the HSHPS organization, for example, could develop consortiums and partnerships with the 20 medical schools in our membership that have a demonstrated commitment to Hispanic health.

Lastly, research skills development and training for medical students and residents is needed to encourage them to consider research careers. The bill could support these efforts through grants to organizations other than biomedical institutions such as the National Hispanic Medical Association and other Hispanic organizations that provide training programs to younger students interested in health careers.

**2. Centers of Excellence for Research Training**—The Health Resources and Services Administration funds Black, Hispanic, Native American and All Minority Centers of Excellence that are granted to health professions schools that have the track record and commitment to recruiting minority students and faculty and developing curriculum and research that focuses on minority populations. The Centers of Excellence have created several innovative accomplishments to enhance diversity training and research for better health system. We applaud the vision behind HR 3250 for challenging the National Institutes of Health to develop a similar program that can only be as successful. We hope that you would support this bill to continue to develop Centers of Excellence programs that encourage research on minority populations.

**3. Medical Education and Health Professions Curriculum**—The eligibility for awards to develop innovative curriculum should not be limited to health professions schools. Residency programs, community based organizations, the health professions associations such as the National Hispanic Medical Association should be allowed to compete for NIH funds and to provide their expertise to the advancement of cultural competence. Indeed the NHMA and the Association of American Indian Physicians wrote a grant to develop cultural competence training of physicians in Orange County, California about heart disease risk factors to the CDC REACH Program. We see our role as sharing expertise in dealing with our communities because we know that there is such a disastrous shortage of minority physicians and other health professionals in the country.

**4. National Cultural Competence Conference**—The national conference by the Office of Minority Health on cultural competence curriculum should not be limited to continuing medical education courses, but should include undergraduate and graduate medical education as well as the other health professions curriculum that are innovative. The Department of Health and Human Services convened a major national conference that brought together the major players in the medical education (licensing, accreditation, medical schools, residency programs, foundations, state government and Federal government) who were encouraged to build innovative curriculum in cultural competence. This leadership needs to be continued at all levels of health professions education. Faculty who teach future providers for the health system need to be educated about successful curricula and to be encouraged by Federal leadership. Hispanic physicians and other minority health providers need to be encouraged to share their vast knowledge base, the “art of medicine” that has not been part of the Western medicine institutionalized information sources—publications, curriculum, mainstream medical specialty and academic conferences. This knowledge is needed especially for the future health providers who will face increasing challenges of diversity in their patients.

**5. Coordination and Dissemination of Cultural Competence Curriculum**—Although we agree that the dissemination function would best be served by the OMH Resource Center, we strongly urge you to support that the coordination function be under the responsibility of the OMH Center for Cultural and Linguistic Competence in Health Care (CCLCHC). The CCLCHC was established by the Office of Minority Health in 1995, upon Congressional mandate. The mission of this CCLCHC is to promote the removal of health care service barriers and increase access to health care for limited English-speaking (LEP), racially and ethnically diverse populations. The CCLCHC should be the focal point for the cultural competence efforts outlined in this legislation and we urge funding for it.

**6. Office of Civil Rights**—Recently, the U.S. Commission on Civil Rights focused attention on Federal health care programs and called for the enhancement of the Office of Civil Rights in order to decrease disparities in health for minorities in the health system. We support the efforts in the bill to expand the efforts of the OCR.

#### CONCLUSION

We have mutual goals with everyone in this room— to increase access to health care services for the most vulnerable and to simultaneously decrease health care costs to our society. After all, creating legislation is an exercise for the public good.



I would argue if we don't pass this legislation, we are asking for greater health care costs to Americans. One cost is the major decrease in individual productivity and a decreased productive workforce. Another cost we would face is drastically reduced public health of all sectors of the population. After all, take a look around at any restaurant, hotel, airport, office buildings, hospitals—the workers are from many countries from around the world with different cultural backgrounds. If they cannot understand our health system because they are not provided appropriate information, or are not comfortable or respected by our physicians and health providers, why would they attempt to obtain medical treatment for TB, Hepatitis, AIDS or debilitating conditions like hypertension, heart disease, asthma, diabetes, cancer, etc.?

HR 3250 is an opportunity to develop strategies to increase knowledge that will improve the quality of life for all minorities in the United States.

We applaud Secretary Donna Shalala and the Department of Health and Human Services under the Clinton administration for laying the foundation for addressing Hispanic health care research and cultural competence through the "Hispanic Agenda for Action." Much more needs to be done by the Department to meet the needs of the growing Hispanic population.

We commend the Chairman of the Subcommittee on Health and Environment, Congressman Bilirakus, and the efforts of Congressman Thompson and the supporters of HR3250 to provide yet another great opportunity for research and cultural competence on Hispanics, African Americans, Asian Americans/Pacific Islanders, and Native Americans to advance knowledge about disease unique to each group, to increase researchers from each group and to develop quality health services with cultural competence training of providers.

The health of all Americans will be enhanced by this bill. We strongly urge all of you to vote for passage of the bill into law.

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Mr. BILIRAKIS. Thank you, Doctor.

Mr. Ignatius Bau, Director of Health Policy, Asian Pacific-Islander American Health Forum, located out of San Francisco, California. Welcome, Mr. Bau. Please proceed, sir.

#### **STATEMENT OF IGNATIUS BAU, DIRECTOR, HEALTH POLICY, ASIAN PACIFIC-ISLANDER AMERICAN HEALTH FORUM**

Mr. BAU. Thank you and good afternoon. Thank you for the opportunity to testify here in support of H.R. 3250. I want to underscore the remarks made by Congressman Underwood earlier this morning, which highlighted many of the points that I'm going to make and which I will not repeat.

We are a national organization that focuses on improving the health of Asian Americans and Pacific Islanders. We work with health providers, community health centers and community based organizations in the diverse Asian American and Pacific-Islander



communities on both health care as well as health promotion and health prevention programs.

We, as Congressman Underwood said this morning, are a very diverse community. We're not a single community, but many, many communities, coming from over 50 countries and speaking over 100 different languages and dialects. As a diverse community, we have very diverse health needs and diverse health statuses. The heterogeneity in our community is reflected in the fact that on the one hand we have stereotypes and images of very successful Asian American doctors and business people.

But on the other hand, we know that southeast Asian women have the highest rates of cervical cancer among all Americans and at the same time have the lowest rates of screening for both breast and cervical cancer. We know that Native Hawaiians consistently suffer much, much worse health than their counterparts in the State of Hawaii. We know that hepatitis B and tuberculosis hit Asian Americans and Pacific-Islanders harder than any other racial and ethnic group. And we know that although one quarter of Asian Americans and Pacific-Islanders in the aggregate are uninsured, over 40 percent of Korean Americans are uninsured mainly because they're in small business and unable to afford health insurance on their own.

Therefore, we wholeheartedly support this bill, H.R. 3250, including the elevation of the Office of Research on Minority Health to a national center on research for minority health and health disparities. Our organization and others have worked with the Office of Research on Minority Health and we know as much as they have done with us and in our community, they need the grant making and the direct authority in order to make sure that the research that we need in our communities to document these health disparities and more importantly, to document interventions that will be effective in addressing these health disparities, are in fact funded and placed in the community where they belong.

We also applaud and very much want to focus on the bill's efforts to collect more complete race and ethnicity data when it comes to health status. This is one of the top priorities for Asian Americans and Pacific-Islanders. Without this data, it's difficult to talk about the diversity of our communities and the diversity of health status in our communities. Because when we're asked, how do you design your program, we need to know which languages and cultures to tailor those programs so that they can reach communities that are most effective. Therefore we very much support the efforts that have been made in the bill and would urge even more efforts to clarify and to even mandate more complete race and ethnicity data regarding health.

Like others on this panel, we support the bill's support for training curricula, particularly for cultural competency, and we also support, along with Dr. Satcher's highlighting it, the media campaign for the Office of Civil Rights. We think that it's very important that the office continue to be supported in its efforts to ensure that the health of all Americans are protected by our civil rights laws.

So in summary, this is long overdue legislation that would go a long way to address many of the health disparities in the Asian



American and Pacific-Islander, as well as the other minority communities in this country, which will go a long way to advancing the health of all Americans.

Thank you.

[The prepared statement of Ignatius Bau follows:]

PREPARED STATEMENT OF IGNATIUS BAU, POLICY DIRECTOR, ASIAN AND PACIFIC ISLANDER AMERICAN HEALTH FORUM

Thank you for the opportunity to testify this morning in support of H.R. 3250. The Asian and Pacific Islander American Health Forum is a national advocacy organization dedicated to promoting policy, program, and research efforts to improve the health and well-being of Asian Americans and Pacific Islanders. Since our inception in 1986, we have worked together with other communities of color to improve the health status of all Americans. In recent years, we have redoubled our collaborative efforts to find common solutions to the difficult challenges in health facing our communities and the nation as a whole.

Before I comment on the Health Care Fairness Act, I would like to provide a brief overview of our Asian American and Pacific Islander communities. We include many diverse peoples, originating from Palau to Pakistan, from American Samoa to Singapore, from Hong Kong to Hawaii. We come from over fifty countries and speak over a hundred different languages and dialects. We are composed of fifth generation Americans, recent immigrants and refugees, and indigenous peoples of the Pacific. According to the U.S. Census Bureau, we are the fastest growing racial/ethnic population in the U.S., expected to increase nearly 40% from 1990 to this year's census.

We also are an incredibly heterogeneous population. As a group, Asian Americans and Pacific Islanders have the highest percentage of college graduates but we also have the highest percentage of those who have less than five years of education.

- Behind the images of immigrant success stories, there are indigenous Pacific Islanders and Southeast Asian refugees that continue to face long-term poverty
  - Behind the images of dot-com South Asian American millionaires, there are Thai Americans who work long hours under extreme conditions in garment factory sweatshops
  - Behind the images of successful Chinese American doctors, there are Korean American grocery store owners who cannot afford any health care
- This great heterogeneity also applies in our health status. For example,
- Native Hawaiian men and women have some of the highest rates of lung cancer incidence and death among all Americans
  - Southeast Asian women have highest rates of cervical cancer among all Americans but at the same time have the lowest rates of breast and cervical cancer screening
  - Asian Americans and Pacific Islanders have the highest rates of tuberculosis and Hepatitis B among all Americans
  - Nearly one quarter of Asian American and Pacific Islanders do not have health insurance

Our organization was established by Asian American and Pacific Islander providers and advocates who came together to address these and other health disparities among Asian American and Pacific Islander populations. We believe that the elimination of health disparities and the improvement of the health of all Americans has to be a united effort. Therefore, we enthusiastically support the Health Care Fairness Act (H.R. 3250).

Specifically, we support the elevation of the Office of Research on Minority Health at the National Institutes of Health (NIH) to a National Center for Research on Minority Health and Health Disparities. We believe that the NIH needs a strong and effective coordinating body to comprehensively plan and implement a health disparities research agenda at the NIH. Moreover, as a member of a population with diverse cultures and languages, we applaud the emphasis on research on the cultural and linguistic aspects of outreach, prevention, and treatment.

We applaud the bill's focus on collecting more complete race and ethnic information regarding health status. This is one of the top priorities for our Asian American and Pacific Islander communities. For too long, the challenges facing many segments of our Asian American and Pacific Islander communities have been ignored because there is no national or local data to document our needs. Moreover, most of the available data do not fully represent the experiences of the diversity in the Asian American and Pacific Islander communities. Without more complete data collection, many Asian American and Pacific Islander communities will not have the



tools to highlight and address the challenges that we face in eliminating health disparities.

We also support the bill's support for training curricula and continuing medical education programs to reduce disparities in health care outcomes, including development of curricula for cultural competency in graduate medical education. It is vital that our current and future health care providers are well-equipped to serve all Americans.

Finally, we strongly support the bill's national media campaign, including the use of ethnic media, to inform the public of the programs and activities of Office of Civil Rights at the Department of Health and Human Services. The Office of Civil Rights already has been working constructively with providers and health care institutions to ensure the civil rights of all Americans in health care settings and its efforts would be enhanced with such additional community awareness and outreach.

This is long overdue legislation that will go a long way in ensuring equal access, quality and outcomes in health care for all Americans. We applaud the co-sponsors of this legislation for coming together to address these challenges collectively. We pledge our cooperation in working with this Committee to secure passage of this bill. Thank you.

Mr. BILIRAKIS. Thank you very much, Mr. Bau.

The Chair recognizes Dr. Coburn to start the questioning.

Mr. COBURN. Thank you, Mr. Chairman.

I just want to touch on one thing with Dr. Rios. Did I hear you say that, maybe it was an implication, that the Federal Government ought to be setting the curricula for the cultural competency? I understand what the bill says, but what did you say?

Ms. RIOS. No, we are supportive of the way the bill is written that the Government should encourage cultural competency curricula, that there is a need for mainstream society to learn more about how to deal with our cultures. What I mentioned was the definition of cultural competency.

Mr. COBURN. I just wanted to clarify that it's not your testimony that the Government ought to be establishing it. The health care professionals who are minorities and know those cultural characteristics ought to be the ones.

Ms. RIOS. Yes. I think the community organizations and the schools need to develop the curricula.

Mr. COBURN. Dr. Peterson, I want to ask you some questions, and I'm very interested in your testimony on HIV. Is it your thought that the disparity is now declining in Virginia because you have a program of HIV and AIDS notification, partner notification and reporting?

Ms. PETERSON. I think it makes a difference. Virginia was one of the first States to have named HIV reporting, so that in the packet of data that you have, if you look at pages 9 and 10 and compare them, you can see that in 1990, we could recognize there was a trend to a racial disparity in the HIV population. We couldn't see that in our AIDS data until, actually it was 1990, for HIV and 1993-94 for AIDS.

That meant that as we used our Ryan White dollars, we could begin to focus resources in our minority population years earlier than other States. So having the data, knowing for all of your different sub-populations, and I would agree with many others on the panel that we need to have that data, did allow us to focus. It has not taken care of all of the disparity in the HIV-AIDS situation. But I think what we try and tease out is access to care, the kinds of things that system wide we can address. It looks like we're doing pretty well because we've been able to focus early.



Mr. COBURN. So basically Virginia is refocusing their dollars where the disease is and in Virginia it happens to be moving into minority populations. But wherever it moved, that you would be able to focus the dollars that way.

Ms. PETERSON. Right. And working in collaboration with consortiums and local groups who then, in that close partnership, can deal with cultural competency as well.

But yes, we have, and one of the maps shows the AIDS cases in the graph for hot spots. We have our resources focused there.

Mr. COBURN. And you do have partner notification law in Virginia?

Ms. PETERSON. Yes.

Mr. COBURN. Did you recall hearing the testimony of Dr. Satcher that he believes, and it's the CDC's position, the name based reporting and partner notification?

Ms. PETERSON. Yes, and I would agree completely. On partner notification, that is how we do all of our sexually transmitted disease. It makes sense for communicable disease control. We've been doing it for a very long time with our HIV name reporting. And we have had no objections to it. We safeguard confidentiality very, very carefully.

Mr. COBURN. Has there ever been a break in confidentiality?

Ms. PETERSON. No, there has not been.

Mr. COBURN. When you report to the CDC on HIV-infected, and somebody contracts it heterosexually, do you report that as a heterosexual transmission?

Ms. PETERSON. We do. Virginia has a slightly different reporting scheme than CDC.

Mr. COBURN. Then let me ask you the question, when the data is received by CDC how do they classify it?

Ms. PETERSON. They probably put it in their other.

Mr. COBURN. Other meaning no identifiable risk?

Ms. PETERSON. Right.

Mr. COBURN. Does that make sense to you as a commissioner of public health?

Ms. PETERSON. What we are trying to do, and made a decision a number of years ago, is to identify for each person what is the mode that they contracted the disease, and therefore, if it's heterosexual transmission, since it's now in the heterosexual population, we wanted to be able to track that.

So we do it a little differently. We know that this is a debate that they are going back to see whether they don't want to go the same direction as Virginia.

Mr. COBURN. Dr. Friedell, a couple questions. We had a little private discussion when I was introduced to you an hour or so ago in terms of human papilloma virus. The House passed yesterday a bill which requires the CDC to now track and develop tools and educational information for the American public on human papilloma virus. I know as you related to me the significant increase you're seeing in cervical cancer in the community that you serve.

One of the things that concerns me, as you talked about cervical cancer and prostate cancer and these other things, is the reports that are out there now that there is a positive correlation between HPV exposure and prostate cancer. When we see the prostate can-



cer, what it is in this country, and we see a sexually transmitted disease that now has a correlation with it, what's your experience now in how we handle HPV in terms of a communicable disease and what we should be doing? Do you have any comments for this Committee in regard to that?

Mr. FRIEDEL. I don't really have any experience as far as prostate cancer and HPV, but I have a fair amount of experience with the idea of human papilloma virus infection when it comes to cancer of the cervix. Cancer of the cervix is at a higher rate in the Appalachian population of Eastern Kentucky. In fact, our own data show that recently, I'm also the director of the State cancer registry, that the incidence of invasive cervical cancer in Eastern Kentucky and Appalachian Kentucky, our rural poor population, is exactly the same as in our African American population.

In terms of HPV and its function, I don't know that we have any reporting mechanism for definition of HPV itself. Until we get a more reliable test, I think in a longer range, most people believe that recognizing human papilloma virus of certain strains, I think it's 16, 18, 31 particularly, that perhaps developing a vaccine is the most effective way to deal with that particular problem as part of the cervical cancer problem.

Mr. BILIRAKIS. I know this is a subject that Dr. Coburn is very knowledgeable in and wants to continue on. But our trouble is, we have probably an hour's worth of votes starting now. I really don't want to make you good people wait until we return.

So possibly if we can maybe hustle right on through.

Mr. Brown.

Mr. BROWN. Thank you.

Mr. Bau, tell me a little bit about tuberculosis, why it's more common among Asian Americans, what nationalities especially does it hit, just the poor who are here, and is there much multi-drug resistant TB among Asian Americans that have contracted it?

Mr. BAU. From what I know, a lot of the tuberculosis is from folks who are coming from other countries where tuberculosis is much more prevalent. So even though we do immigration screening for that, a lot of that, and Dr. Peterson could probably speak to it as well, it means that we then need both culturally appropriate as well as linguistically appropriate programs to follow up to make sure people continue to stay on their medications.

And also the conditions where tuberculosis continues to spread, where there's overcrowding, where there's not good ventilation. When you've got new immigrant populations coming in, housing situations in which those kinds of situations do exist, then that also leads to the spread, even again to the best efforts.

So again, a lot of it is targeting the efforts. I think Dr. Peterson could also speak to the fact that our funding for tuberculosis control was at a really good level and then it fell dramatically several years ago. So again, part of the resurgence that we see is directly correlated to the amount of funding that goes into those programs.

Mr. BROWN. Dr. Peterson, comment if you would, and also, are we doing directly observed treatment well in Virginia?

Ms. PETERSON. We are doing directly observed treatment for cases that are infectious. The resource funding issue is a limiting factor for skin test positive, but non-infectious cases, and doing di-



rectly observed therapy. I would reiterate that in Virginia, our cases are foreign borne at this point. One of our measures of success is finding them, treating them early and making sure that we don't have any cases that are transmission within the U.S. Virginia has been very successful with that. It's getting harder to do.

Mr. BROWN. Thank you, Mr. Chairman.

Mr. BILIRAKIS. Dr. Cohen, your organization, AAMC, has traditionally opposed set-aside programs for research that is not reviewable by research management. We've had a policy here in the Congress, of not directing NIH on how they should spend those research dollars, even though we sometimes are unhappy about some of the decisions they make, and we let them know that. But we still hesitate to direct that.

Yet this legislation, as you know, allocates funds directly to the proposed center. Comment quickly?

Mr. COHEN. Well, I think the decision we came to was that the urgency of this matter was such that we were willing to forego that traditional objection to bypass budgets, which we continue to have a strong policy against. But we feel that the balance here has shifted because of the urgency of this issue.

Mr. BILIRAKIS. The urgency, then. I see.

Well, I have so much more, but the Chair is going to recognize Mr. Whitfield.

Mr. WHITFIELD. Mr. Chairman, thank you, and I understand you're going to relieve this panel.

Mr. BILIRAKIS. Yes, we're going to finish up.

Mr. WHITFIELD. I would first of all ask unanimous consent that Dr. Friedell be able to admit into the record an article from the Lexington Herald relating to incidence of cancer within the State of Kentucky.

Mr. BILIRAKIS. Without objection. And to add to that, there is a package here which has been cleared through the Minority National Alliance of State Territorial AIDS Directors, the data and testimony of Thomas Liberti, Chief, Bureau of HIV-AIDS in Florida. I would ask unanimous consent that that be made a part of the record. It has been cleared.

Mr. WHITFIELD. Mr. Chairman, I'm just going to make one statement. I read Dr. Friedell's testimony, and I think everyone on this panel would agree that we are very much concerned about the programs for research and health, prevention of disease in minorities. I think it's also important, and Dr. Friedell pointed this out very well, that we be concerned about all underserved populations, whatever their ethnicity might be.

There are, as a matter of fact, more poor white people underserved in the country than there are blacks, Hispanics, Native Americans put together. And this bill focuses entirely on minorities, which is important. But I think we also, as we move forward in this legislation, must focus on the medically underserved as well.

Mr. BILIRAKIS. Mr. Strickland.

Mr. STRICKLAND. I just want to make one quick statement. We only have a couple of minutes left. But I'm going to echo my colleague's comments. I believe we need to focus on minority health.



I believe the statistics are alarming and unacceptable that you have talked about.

I also believe, talking to Dr. Friedell and others, that correlation is not necessarily causation, and race and ethnicity may not be the primary causative factor. It may be medically underserved populations and poverty related conditions. So I hope this bill is not so limited that it leaves out a whole mass of citizens who rightfully should be considered as being underserved.

Mr. BILIRAKIS. I appreciate that, Mr. Strickland.

Very quickly, and I don't know how much time we have, we don't have very much, but if the elevation of the office to center is a potential stumbling block because of the fact that dollars bypass the director, etc., and unless we get the administration's approval, I don't know really how much hope there will be.

So I would ask you about the other provisions of this bill, Title II, Title III, Title IV, and Title V. Do you feel there's a lot to be gained by those titles and can be gained from a constructive basis, whether or not at this time the office is elevated to center?

[All witnesses respond in the affirmative.]

Mr. BILIRAKIS. You all do, then. Thank you.

Well, ladies and gentlemen, we really appreciate it. We apologize for your waiting so long. Some of you have had this experience before and know what it's like up here.

Also, we do ask that you be willing to answer any written requests to you. You've been an awful lot of help. Thank you so much. The hearing is adjourned.

[Whereupon, at 3:07 p.m., the subcommittee was adjourned.]

[Additional material submitted for the record follows:]

#### COORDINATION OF MINORITY HEALTH ACTIVITIES WITHIN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

The Department of Health and Human Services (DHHS) utilizes both formal and informal strategies to accomplish the coordination of minority health activities in a timely, efficient, and effective manner.

In 1998, the Secretary established an infrastructure to institutionalize the White House minority initiatives within each operating division of the Department. This included the initiatives for: Historically Black Colleges and Universities (HBCU), the Hispanic Agenda for Action (HAA), the White House Initiative on Tribal Colleges and Universities, and the Asian American and Pacific Islander Action Agenda. This formal structure was also established to improve coordination of issues and activities that crossed all four initiatives.

To fulfill the above goals, a Departmental Minority Initiatives Steering Committee was established to provide direction and guidance for the initiatives. This Committee is composed of the Heads or Deputies of the DHHS Operating Divisions; the Assistant Secretaries for Management and Budget, Planning and Evaluation, and Health/Surgeon General; and senior staff members from the Executive Secretariat, Office for Civil Rights, Office of the General Counsel, and the Office of Intergovernmental Affairs. The Deputy Secretary chairs the Committee, and the Deputy Assistant Secretary for Minority Health serves as its Executive Director. This Committee meets on a quarterly basis.

Supporting this Steering Committee is the Departmental Minority Initiatives Coordinating Committee (DMICC) which acts as the coordinating body and meets monthly. The Department's Office of Minority Health (OMH) is responsible for providing staff support to both the DMICC and the Steering Committee, and plays a lead role in the ongoing management of all minority initiatives. The body of this committee is made up of senior level staff members who are responsible for the management of minority health activities within the DHHS Operating Divisions. In addition, on an as needed basis, subcommittees or work groups are created to better address issues that intersect the four initiatives, and allows for additional input from the targeted racial/ethnic groups.



The Operating Divisions also coordinate activities among themselves in instances where a Department-wide plan is not involved. Again, these coordination activities may occur informally or through more formal means such as an interagency agreement for cofunding a program or project. OMH has also established cooperative agreements with minority organizations, which allows offices and agencies to collaborate in the conduct of mutually inclusive initiatives for improving the health status and quality of life for racial/ethnic populations. In addition, the Operating Divisions often utilize the DMICC meeting as an avenue for sharing information regarding minority health activities within their respective agencies.

All of these formal and informal procedures have been instituted to ensure that greater coordination exists throughout DHHS. These activities also ensure that those individuals within each agency with the appropriate knowledge and experience are involved in developing, coordinating, and reporting on the Department's efforts to address the health needs of minority communities.

#### DHHS MINORITY HEALTH DIRECTORS AND ADMINISTRATORS

Agency	Location Of Minority Health Activities	Contact Person	Telephone Number
DHHS/OS ..	Office of Minority Health, Office of Public Health and Science	Nathan Stinson Ph.D., M.D., M.P.H., Deputy Assistant Secretary for Minority Health	301-443-5084
FDA .....	Office of Consumer Affairs	Mary Wallace, Director of Consumer Programs	301-827-4406
NIH .....	Office of Research on Minority Health, Office of the Director	John Ruffin, Ph.D., Director	301-402-1366
IHS .....	External Affairs, Office of the Director	Leo Nolan, Senior Policy Analyst (contact is usually issue specific)	301-443-7261
ATSDR .....	Office of Urban Affairs	Vincent Nathan, Ph.D., M.P.H., Minority Health Program Manager	404-639-5064
AHRQ .....	Center for Cost and Financing Studies	Morgan Jackson, M.D., Minority Health Program Director	301-594-0147
HRSA .....	Office of Minority Health, Office of the Administrator	M. June Horner, Director	301-443-2964
AoA .....	Office of the Assistant Secretary	Sunday Mezurashi, Special Assistant to the Assistant Secretary	202-401-4541
HCFA .....	Beneficiary Services Group, Center for Beneficial Services	Kevin Nash, Program Executive for Minority Health Initiatives	410-786-5781
CDC .....	Office of Minority Health, Office of the Director	Wilma Johnson, MSPH, Acting Associate Director	404-639-7210
SAMHSA ...	Office of Minority Health, Office of the Administrator	Deloris Hunter, Ph.D., Director	301-443-7265

ACADEMIC HEALTH CENTERS  
May 10, 2000

The Honorable MICHAEL BILIRAKIS  
Subcommittee on Health and Environment  
Committee on Commerce  
2125 Rayburn House Office Building  
United States House of Representatives  
Washington, D.C. 20515

DEAR MR. CHAIRMAN: The Association of Academic Health Centers is writing to express our support for H.R. 2391 and H.R. 3250, bills that would elevate the Office of Research on Minority Health at the National Institutes of Health to a National Center.

Health status disparities in the United States among minority, disadvantaged, and underserved communities continue to persist, even though improvements have been made in the general population.

By elevating the existing NIH office to a center, research on health disparities will be a higher priority, and the community will be empowered to take responsibility to achieve the national goal of improving the health status of all Americans. As you know, the goal of Healthy People 2010 is to eliminate disparities in health.

AAHC requests that you make this letter a part of the record for your subcommittee's May 11th hearing on health status disparities.



Thank you for the opportunity to present our views.

Sincerely,

ROGER J. BULGER, MD  
*President*

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PREPARED STATEMENT OF LORETTA DAVIS-SATTERLA, DIRECTOR, DIVISION OF HIV/  
AIDS-STD, MICHIGAN DEPARTMENT OF COMMUNITY HEALTH

AIDS case reporting has been the cornerstone of national efforts to monitor the spread and impact of the HIV/AIDS epidemic. In the past, monitoring AIDS-defining conditions provided population-based data that reflected changes in the incidence of HIV infection. However, recent advances in HIV treatment have slowed the progression of HIV disease and has contributed to a decline in AIDS incidence. Thus, AIDS case reporting provides information on an epidemic which is a decade or more old. Advances in treatment have diminished the ability of AIDS surveillance data to represent trends in the incidence of HIV infection and as a consequence, the capacity of local, state, and federal public health agencies to monitor the HIV epidemic has been compromised.

Surveillance activities are a key element of a comprehensive public health response to this epidemic. Surveillance data assists public health in monitoring the epidemic including the number of people infected, the number of newly acquired infections and the modes of transmission. In addition, the data is used to target and evaluate prevention and care efforts, and in the allocation of resources.

In Michigan, confidential HIV reporting has been required by statute since 1989. Confidential HIV reporting has greatly enhanced Michigan's ability to rapidly and effectively respond to the dynamics of this epidemic. It is estimated that there are currently 13,000 individuals residing in Michigan who are infected with HIV. The HIV/AIDS Reporting System (HARS) reveals that there are 4,433 currently living with AIDS and an additional 4,830 individuals living with HIV and not AIDS. In contrast to AIDS case surveillance, HIV case surveillance provides data to better characterize populations in which HIV infection has been newly diagnosed, including persons with evidence of recent HIV infection. Compared with persons living with AIDS, those reported living with HIV infection in Michigan are more likely to be women (18% for AIDS vs 26% for HIV) and African Americans (55% for AIDS and 62% for HIV). Approximately, 1% of AIDS cases occurred in both persons aged 13-19 years and 20-24 years. In comparison, 4% of HIV cases occurred in persons aged 13-19 years and 13% of HIV cases occurred in persons 20-24 years. Thus, AIDS case surveillance alone does not accurately reflect the extent of the HIV epidemic among African Americans, women, adolescents and young adults.

Having knowledge about those more recently infected with HIV, with respect to risk as well as sociocultural characteristics, is exceedingly important in targeting prevention efforts. HIV case data facilitate identification of trends in the epidemic. As a direct result of having HIV case data available for planning efforts, current prevention efforts supported by the Michigan Department of Community Health emphasize racial/ethnic minorities, women and at-risk youth. Having a snap-shot of an emerging epidemic has also facilitated development of prevention interventions which are responsive to community needs, as well as being culturally and linguistically competent. HIV case data, combined with other types of data, has guided allocation of prevention resources to address priority needs and communities. Confidential HIV case data have also been critical in planning and evaluating continuum of care efforts.

Michigan is fortunate to have a statewide client-level data collection system (the Uniform Reporting System or URS) which documents the service utilization patterns of persons living with HIV/AIDS (PLWH/A) who access service programs funded through the Ryan White CARE Act. The URS data, when used in conjunction with HIV/AIDS surveillance data, allow us to evaluate whether the HIV/AIDS Continuum of Care system is reaching the population known to be living with the disease. Because client descriptive information is linked to service data, the URS allows us to review how intensively different subsets of the population are utilizing different components of the care system, and it can also be used to identify gaps in service to specific groups or in specific areas.

The URS and HIV/AIDS Reporting System (HARS) case report data are compared at least annually to ascertain whether the population receiving services is consistent demographically with the cases reported in each region and the state, and to verify whether minority and historically underserved populations have been served in proportion to their representation in the community of persons living with HIV infection and/or AIDS. Over the last several years this comparison has revealed that cli-



ents served by RWCA-funded agencies were representative of the HIV epidemic in Michigan.

As the proportions of women and African Americans have increased in the epidemic, they have also increased in URS data, indicating a growing need for services among these populations. For example, the percent of African Americans served went from 56.6% of the total in 1995 to 63% of the total served in 1999, and the number served increased by 35% (3,066 to 4,143). The proportion of Hispanic clients served has also increased slightly, going from 3.1% (1995) to 3.6% of the total served (1999), with the number served increasing by 43% (166 to 238). The number of women (of all races) served in 1999 was 40.6% more than the number reported in 1995 (1,176 to 1,653). Females made up 26% of the total served during 1999 while they were only 21.7% of the total served during 1995.

The fact that URS data and HARS data report similar demographic proportions for the known infected population and the population reported to be "in care" indicates that the continuum of care system in Michigan has been successful at reaching and serving people who are representative of the epidemic in the state. Without client-level data and HIV case reporting this type of evaluation would not be possible.

African Americans and women of all races have been described as "traditionally under served populations" and this designation has considerable basis in fact, especially for those who are also living with HIV disease. Effectively treating HIV and all its physical symptoms is difficult, but when exacerbating co-morbidities or socioeconomic conditions (such as poverty, homelessness, or lack of insurance) are also present, the range of available treatment options becomes significantly more limited and the challenge of providing quality care is compounded exponentially. Simply put, co-morbidities and other co-factors increase the complexity and the cost of care for persons living with HIV. A significant proportion of PLWH/A, effected by one or more of these co-morbidities or socioeconomic factors, are African Americans and women.

The URS data over the past five years have documented that poverty, lack of health insurance, the presence of mental health and/or substance abuse problems, and homelessness/inadequate housing are factors which effect a higher proportion of African Americans living with HIV and women living with HIV than the general HIV/AIDS affected population who use Ryan White funded services.

Poverty is the co-factor which effects the largest percentage of persons living with HIV. Poverty creates significant barriers to care because it effects every aspect of life, beginning with lack of health insurance, and transportation to medical care, and extending to poor nutrition, inadequate housing and generally poor health practices due to lack of resources.

Substance abuse, and/or mental illness also have a serious impact on the complexity of care for people with HIV. Substance abuse or mental health issues are difficult to treat individually and often have a negative impact on an individual's health since either co-morbidity can effect a person's ability to adhere to treatment and remain in care. In addition, substance abusers or the mentally ill often have unstable living conditions, which makes follow-up difficult.

When seeking to address these issues, with the goal of achieving 100% access and 0% disparity, it is essential that systems are utilized that allow identification of emerging trends relative to race/ethnicity, gender and behavioral risk factors. Planning based on trends in HIV infection provides a more accurate assessment of the distribution of the infected population, the number of individuals in need of access to treatment, and the type of medical and support services required to meet client needs. In Michigan, HIV case reporting and the Uniform Reporting System have been effective tools in addressing the current epidemic by facilitating planning of appropriate prevention, early intervention and care services. Michigan has documented that the combined prevalence of those living with a diagnosis of HIV infection and those living with AIDS provides a more realistic and useful estimate of the resources needed for prevention and care services than does AIDS prevalence alone.



## NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

May 11, 2000

The Honorable THOMAS BILEY  
*Chairman*  
*House Commerce Committee*  
*U.S. House of Representatives*  
*Washington, DC 20515*

The Honorable MICHAEL BILIRAKIS  
*Chairman*  
*Health and Environment Subcommittee*  
*U.S. House of Representatives*  
*Washington, DC 20515*

DEAR CHAIRMAN BILEY AND CHAIRMAN BILIRAKIS: On behalf of the National Alliance of State and Territorial Directors, I am requesting submission for the record HIV/AIDS surveillance information that illustrates disparities among racial/ethnic minorities in terms of HIV/AIDS in the U.S. The attached tables provide data on the percentage comparison of individuals living with AIDS, and the percentage of individuals diagnosed with HIV (not AIDS) based on race and sex for the 25 States that had initiated HIV reporting before 1995.

Confidential HIV reporting enhances the ability of public health programs to rapidly and effectively respond to the dynamics of the HIV/AIDS epidemic. HIV case surveillance provides data to better characterize and deliver services to populations in which HIV infection has been newly diagnosed, including persons with evidence of recent HIV infection. The data compiled in these tables generally indicate that compared with persons living with AIDS, those reported living with HIV infection are more likely to be people of color and women. The data suggest that AIDS case surveillance alone does not accurately reflect the extent of the HIV epidemic among African Americans, Hispanics and women in the United States.

Having knowledge about those more recently infected with HIV in terms of risk factors and socio-cultural characteristics is important in targeting prevention and treatment programs. Planning based on trends in HIV infection provides a more accurate assessment of the distribution of infected populations, the number of individuals in need of access to treatment, and the type of medical and support services required to meet client needs through programs such as those funded by the Ryan White CARE Act.

Thank you for the opportunity to submit this information for the committee consideration.

Sincerely,

JULIE M. SCOFIELD  
*Executive Director*

## Alabama Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	37.6%	White .....	35.2%
Black .....	60.9%	Black .....	62.2%
Hispanic .....	1.2%	Hispanic .....	0.8%
Asian .....	0.2%	Asian .....	0.1%
Indian .....	0.1%	Indian .....	0.1%
Unknown .....	0.0%	Unknown .....	1.5%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	81.4%	Male .....	74.2%
Female .....	18.6%	Female .....	25.8%

## Arkansas Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	61.4%	White .....	53.0%
Black .....	36.2%	Black .....	43.7%
Hispanic .....	1.4%	Hispanic .....	0.9%
Asian .....	0.1%	Asian .....	0.1%



## Arkansas Profile—Continued

AIDS Prevalence by Race		HIV Prevalence by Race	
Indian .....	0.5%	Indian .....	0.2%
Unknown .....	0.3%	Unknown .....	2.2%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	82.5%	Male .....	75.2%
Female .....	17.5%	Female .....	24.8%

## Arizona Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	69.5%	White .....	66.1%
Black .....	8.0%	Black .....	10.5%
Hispanic .....	19.5%	Hispanic .....	16.4%
Asian .....	0.7%	Asian .....	0.5%
Indian .....	2.2%	Indian .....	2.9%
Unknown .....	0.1%	Unknown .....	3.5%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	89.8%	Male .....	86.2%
Female .....	10.2%	Female .....	13.8%

## Colorado Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	70.5%	White .....	71.2%
Black .....	13.2%	Black .....	13.4%
Hispanic .....	15.3%	Hispanic .....	12.1%
Asian .....	0.4%	Asian .....	0.4%
Indian .....	0.6%	Indian .....	0.7%
Unknown .....	0.0%	Unknown .....	2.2%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	91.5%	Male .....	91.3%
Female .....	8.5%	Female .....	8.7%

## Idaho Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	83.6%	White .....	85.1%
Black .....	2.6%	Black .....	5.5%
Hispanic .....	11.8%	Hispanic .....	8.4%
Asian .....	1.0%	Asian .....	0.0%
Indian .....	1.0%	Indian .....	0.7%
Unknown .....	0.0%	Unknown .....	0.4%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	85.2%	Male .....	83.6%
Female .....	14.8%	Female .....	16.4%



## Indiana Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	69.3%	White .....	60.7%
Black .....	26.5%	Black .....	35.2%
Hispanic .....	3.9%	Hispanic .....	3.6%
Asian .....	0.1%	Asian .....	0.3%
Indian .....	0.2%	Indian .....	0.1%
Unknown .....	0.0%	Unknown .....	0.1%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	88.2%	Male .....	82.4%
Female .....	11.8%	Female .....	17.6%

## Louisiana Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	40.4%	White .....	29.2%
Black .....	56.3%	Black .....	67.7%
Hispanic .....	2.8%	Hispanic .....	2.4%
Asian .....	0.2%	Asian .....	0.2%
Indian .....	0.1%	Indian .....	0.1%
Unknown .....	0.2%	Unknown .....	0.3%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	81.4%	Male .....	68.3%
Female .....	18.6%	Female .....	31.7%

## Michigan Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	41.3%	White .....	33.6%
Black .....	55.0%	Black .....	61.3%
Hispanic .....	3.4%	Hispanic .....	3.0%
Asian .....	0.3%	Asian .....	0.1%
Indian .....	0.1%	Indian .....	0.6%
Unknown .....	0.0%	Unknown .....	1.4%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	81.9%	Male .....	74.6%
Female .....	18.1%	Female .....	25.4%

## Minnesota Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	66.8%	White .....	61.0%
Black .....	23.8%	Black .....	28.7%
Hispanic .....	6.5%	Hispanic .....	6.3%
Asian .....	0.8%	Asian .....	0.9%
Indian .....	2.1%	Indian .....	2.2%
Unknown .....	0.0%	Unknown .....	0.9%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	86.5%	Male .....	82.8%
Female .....	13.5%	Female .....	17.2%



## Missouri Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	60.9%	White .....	53.1%
Black .....	35.4%	Black .....	43.0%
Hispanic .....	3.1%	Hispanic .....	2.6%
Asian .....	0.3%	Asian .....	0.4%
Indian .....	0.4%	Indian .....	0.2%
Unknown .....	0.1%	Unknown .....	0.7%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	88.9%	Male .....	84.4%
Female .....	11.1%	Female .....	15.6%

## Mississippi Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	31.6%	White .....	23.7%
Black .....	66.8%	Black .....	73.7%
Hispanic .....	1.2%	Hispanic .....	1.1%
Asian .....	0.1%	Asian .....	0.2%
Indian .....	0.2%	Indian .....	0.1%
Unknown .....	0.2%	Unknown .....	1.1%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	75.7%	Male .....	68.4%
Female .....	24.3%	Female .....	31.6%

## North Carolina Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	28.8%	White .....	22.3%
Black .....	67.1%	Black .....	74.8%
Hispanic .....	2.9%	Hispanic .....	1.0%
Asian .....	0.2%	Asian .....	0.3%
Indian .....	0.7%	Indian .....	0.9%
Unknown .....	0.3%	Unknown .....	0.7%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	77.6%	Male .....	65.0%
Female .....	22.4%	Female .....	35.0%

## North Dakota Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	73.2%	White .....	81.7%
Black .....	7.3%	Black .....	6.7%
Hispanic .....	4.9%	Hispanic .....	3.3%
Asian .....	2.4%	Asian .....	0.0%
Indian .....	12.2%	Indian .....	6.7%
Unknown .....	0.0%	Unknown .....	1.7%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	87.8%	Male .....	81.7%
Female .....	12.2%	Female .....	18.3%



## New Jersey Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	25.8%	White .....	19.1%
Black .....	54.2%	Black .....	58.3%
Hispanic .....	19.2%	Hispanic .....	20.4%
Asian .....	0.4%	Asian .....	0.5%
Indian .....	0.1%	Indian .....	0.1%
Unknown .....	0.3%	Unknown .....	1.6%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	68.5%	Male .....	59.8%
Female .....	31.5%	Female .....	40.2%

## Nevada Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	63.3%	White .....	64.0%
Black .....	20.8%	Black .....	22.7%
Hispanic .....	13.8%	Hispanic .....	11.3%
Asian .....	1.3%	Asian .....	1.0%
Indian .....	0.8%	Indian .....	0.8%
Unknown .....	0.0%	Unknown .....	0.2%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	86.9%	Male .....	81.7%
Female .....	13.1%	Female .....	18.3%

## Ohio Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	56.6%	White .....	43.2%
Black .....	38.2%	Black .....	46.3%
Hispanic .....	4.7%	Hispanic .....	4.2%
Asian .....	0.3%	Asian .....	0.2%
Indian .....	0.1%	Indian .....	0.2%
Unknown .....	0.0%	Unknown .....	5.9%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	85.8%	Male .....	77.4%
Female .....	14.2%	Female .....	22.6%

## Oklahoma Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	69.7%	White .....	65.7%
Black .....	17.8%	Black .....	23.7%
Hispanic .....	4.6%	Hispanic .....	3.8%
Asian .....	0.7%	Asian .....	0.4%
Indian .....	7.0%	Indian .....	5.8%
Unknown .....	0.2%	Unknown .....	0.6%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	88.2%	Male .....	84.1%
Female .....	11.8%	Female .....	15.9%



## South Carolina Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	28.6%	White .....	25.6%
Black .....	69.9%	Black .....	73.0%
Hispanic .....	1.3%	Hispanic .....	1.0%
Asian .....	0.1%	Asian .....	0.2%
Indian .....	0.1%	Indian .....	0.1%
Unknown .....	0.0%	Unknown .....	0.3%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	75.4%	Male .....	68.7%
Female .....	24.6%	Female .....	31.3%

## South Dakota Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	82.5%	White .....	79.5%
Black .....	4.8%	Black .....	8.1%
Hispanic .....	3.2%	Hispanic .....	3.7%
Asian .....	0.0%	Asian .....	0.0%
Indian .....	9.5%	Indian .....	8.7%
Unknown .....	0.0%	Unknown .....	0.0%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	85.7%	Male .....	82.0%
Female .....	14.3%	Female .....	18.0%

## Tennessee Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	49.8%	White .....	39.1%
Black .....	48.3%	Black .....	59.6%
Hispanic .....	1.5%	Hispanic .....	1.1%
Asian .....	0.2%	Asian .....	0.2%
Indian .....	0.1%	Indian .....	0.0%
Unknown .....	0.0%	Unknown .....	0.0%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	83.6%	Male .....	72.6%
Female .....	16.4%	Female .....	27.4%

## Utah Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	79.6%	White .....	77.3%
Black .....	6.6%	Black .....	9.1%
Hispanic .....	11.7%	Hispanic .....	11.2%
Asian .....	0.8%	Asian .....	0.3%
Indian .....	1.3%	Indian .....	1.8%
Unknown .....	0.0%	Unknown .....	0.4%

AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	91.4%	Male .....	85.6%
Female .....	8.6%	Female .....	14.4%



## Virginia Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	38.1%	White .....	29.6%
Black .....	57.3%	Black .....	65.8%
Hispanic .....	3.8%	Hispanic .....	3.0%
Asian .....	0.6%	Asian .....	0.5%
Indian .....	0.1%	Indian .....	0.1%
Unknown .....	0.1%	Unknown .....	0.9%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	80.7%	Male .....	72.4%
Female .....	19.3%	Female .....	27.6%

## Wisconsin Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	54.8%	White .....	48.3%
Black .....	34.4%	Black .....	41.9%
Hispanic .....	9.4%	Hispanic .....	7.7%
Asian .....	0.4%	Asian .....	0.8%
Indian .....	0.8%	Indian .....	1.1%
Unknown .....	0.1%	Unknown .....	0.3%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	86.8%	Male .....	79.4%
Female .....	13.2%	Female .....	20.6%

## West Virginia Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	79.3%	White .....	58.4%
Black .....	19.3%	Black .....	37.2%
Hispanic .....	1.1%	Hispanic .....	2.3%
Asian .....	0.0%	Asian .....	0.4%
Indian .....	0.0%	Indian .....	0.2%
Unknown .....	0.2%	Unknown .....	1.5%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	86.0%	Male .....	71.3%
Female .....	14.0%	Female .....	28.7%

## Wyoming Profile

AIDS Prevalence by Race		HIV Prevalence by Race	
White .....	88.9%	White .....	76.3%
Black .....	4.8%	Black .....	6.8%
Hispanic .....	6.3%	Hispanic .....	13.6%
Asian .....	0.0%	Asian .....	1.7%
Indian .....	0.0%	Indian .....	1.7%
Unknown .....	0.0%	Unknown .....	0.0%
AIDS Prevalence by Sex		HIV Prevalence by Sex	
Male .....	92.1%	Male .....	79.7%
Female .....	7.9%	Female .....	20.3%

AIDS prevalence as of 12/1998; prevalence of diagnosed HIV (not AIDS) as of 12/1998.



Source: Centers for Disease Control and Prevention (CDC)

NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS, INC.<sup>®</sup>  
*May 11, 2000*

The Honorable MIKE BILIRAKIS, Chair  
 The Honorable SHERROD BROWN, Ranking Member  
*Subcommittee on Health and Environment*  
*House Commerce Committee*  
*2125 Rayburn House Office Building*  
*Washington, DC 20515*

DEAR CHAIRMAN BILIRAKIS, RANKING MEMBER BROWN, AND MEMBERS OF THE SUBCOMMITTEE: Thank you for providing an opportunity for us to submit a statement on behalf of the National Association of Community Health Centers regarding H.R. 3250, the "Health Care Fairness Act of 1999." We appreciate your consideration of our views.

We strongly support the goal of this legislation: to reduce and eventually eliminate the health disparities that currently exist between white Americans and those who are members of a racial or ethnic minority. For more than thirty years, community, migrant and homeless health centers have been working toward that goal. The goal of the national health center program is to provide, "100% Access" to health care with "Zero health disparities."

Health centers provide high quality primary care to people of all ages, from all cultures, and with all incomes. Health centers are the health care home for nearly 4.5 million children 7 million people of color, over 600,000 farmworkers, and more than a half-million homeless men, women, and children each year—11 million patients in all, 4.5 million of whom are uninsured.

We take pride in the successes we have had thus far in developing and implementing service delivery models that are notable for helping to reduce some of the gaps that exist in health outcomes for minorities today. Some of our accomplishments include: dramatic reductions in infant mortality rates; successful management of diabetes, hypertension, and asthma that afflicts many of our patients from racial and ethnic minority groups; childhood immunization rates that shame the industry standard; and increased usage of prenatal care and preventive health strategies by health center patients.

However, we claim only to have been consistent warriors in this battle, with some successful fighting techniques to share. Our nation is far away from winning the war against health disparities. Therefore, we applaud the Subcommittee for its bold vision and its willingness to take a stand on these issues by convening today's hearing on H.R. 3250.

Without question, more research in this field needs to be done. We applaud the sponsors of this legislation for proposing the creation of the National Center for Research on Minority Health and Health Disparities. We believe such a Center is long overdue. However, NACHC strongly urges the Committee to clearly convey its intent to appropriators that funding for this Center should, to the extent possible, be dedicated out of the existing budget for the National Institutes of Health so as not to undermine funding for other important programs funded under the Labor, Health and Human Services, and Education Appropriations bill.

There are several important sections in the legislation that provide for the support and conduct of research and demonstration programs to test and evaluate strategies for eliminating health disparities and for promoting effective interventions. We believe health centers are well situated to be given priority consideration as demonstration test sites for the research models funded under this bill.

We also support adding a new requirement to the bill that would call for the collection of data and information on best practice models of service delivery where disparities in health outcomes are currently being addressed, such as at federally qualified health centers.

We appreciate the inclusion of health centers among the provider groups named as eligible entities to receive incentives under a new program that would encourage health care professionals to participate in continuing medical education programs designed to decrease disparities in minority health.

And finally, we would encourage changes to the legislation that would include participation from health center experts on the new advisory committee to the Secretary of Health and Human Services, as well as in the development of and participation in the national conference on continuing medical education on cultural competency that is mandated under the bill. Health center clinicians and directors have years of valuable, field-tested experience in providing culturally competent care.



Failure to include their expertise in these endeavors would be an unfortunate oversight.

In sum, the National Association of Community Health Centers would encourage the Subcommittee to move forward with favorable consideration of this legislation, including any of the suggested changes we have outlined in this statement. We believe H.R. 3250 is a good bill and deserves to become law.

This Congress has an opportunity to right many of the wrongs that exist in today's healthcare system. Taking action to reduce and eliminate racial disparities in health outcomes is a good step in the right direction.

Again, thank you for this opportunity to share our thoughts with you.

Sincerely,

CAROLYN EMANUEL-McCLAIN  
*Chair, National Board of Directors, NACHC*  
*Executive Director, Family Health Centers, Inc. NACHC*  
*Orangeburg, South Carolina*  
TOM VAN COVERDEN  
*President and CEO, NACHC*

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NATIONAL MEDICAL ASSOCIATION  
WASHINGTON, D.C.  
May 11, 1999

The Honorable MICHAEL BILIRAKIS  
*Chairman,*  
*House Committee on Commerce,*  
*Subcommittee on Health and the Environment*  
2125 Rayburn House Office Building  
Washington, D.C. 20515

DEAR MR. CHAIRMAN: The National Medical Association (NMA) is very pleased to support H.R. 2391 and H.R. 3250, bills which would elevate the Office of Research on Minority Health (ORMH) at the National Institutes of Health (NIH) to a National Center.

In spite of the fact that the nation has experienced tremendous advances in biomedical research, the benefits of these advances have not fully translated into better health status or health care for African Americans and other racial and ethnic minorities. Communities of color continue to be unduly plagued with disproportionate rates of death and disease. As the changing demographics of the nation yield an increasingly diverse U.S. population, it is absolutely essential that the nation become increasingly proactive in addressing the critical health and biomedical research needs of communities of color.

By elevating the existing NIH office to a center, research on health disparities will be a higher priority, and communities of color will be empowered to take responsibility to achieve the national goal of closing the health disparity gap.

In reference to today's hearing on H.R. 3250, the NMA supports the critical provisions of this critical legislation, which include:

- The establishment of the Center for Research on Minority Health and Health Disparities at the National Institutes of Health (NIH);
- The provision of funds to support programs of excellence in biomedical research and for peer-reviewed minority health-focused research grants;
- The requirement to establish a comprehensive plan and budget for the conduct and support of all minority research activities of the NIH agencies; and
- The establishment of a grant program to support the development of culturally competent curricula in health care education.

The NMA strongly supports both legislative measures and believes that they will create important opportunities for the nation to make concrete advances in its effort to close the health disparity gap. NMA would appreciate it if you would include this letter in the record for your subcommittee's May 11th hearing on H.R. 3250, the Health Care Fairness Act. We look forward to working with you to ensure passage and enactment of this important bill.

Sincerely,

JAVETTE ORGAIN, M.D.  
*President*



RESEARCH!AMERICA  
May 10, 2000

The Honorable MICHAEL BILIRAKIS  
Subcommittee on Health and Environment  
Committee on Commerce  
2125 Rayburn House Office Building  
United States House of Representatives  
Washington, D.C. 20515

DEAR MR. CHAIRMAN: *Research!America* is writing to stress the importance of consideration of H.R. 2391 and H.R. 3250, bills which would elevate the Office of Research on Minority Health (ORME) at the National Institutes of Health (NIH) to a National Center.

Health status disparities in the United States among minority, disadvantaged, and under served communities continue to persist, even though improvements have been made in the general population. According to our polls, the top health concerns of American citizens are the very diseases which disproportionately affect minority and under served populations such as cancer and AIDS.

It is time this nation makes research on health disparities a higher priority so the community will be empowered to achieve the goal of improving the health status of all Americans.

*Research!America* would appreciate it if you would make this letter a part of the record for your subcommittee's May 11 hearing on health disparities.

Thank you for the opportunity to present our views.

Sincerely,

PAUL G. ROGERS

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PREPARED STATEMENT OF GLORIA M. RODRIGUEZ, ASSISTANT COMMISSIONER, NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES, DIVISION OF AIDS PREVENTION AND CONTROL

I welcome the opportunity to comment on H.R. 3250, the Health Care Fairness Act of 1999. It has long been an "accepted" fact that many diseases disproportionately affect minorities. I use the term "accepted" purposefully, as it reflects society's lack of concern at the results of these disparities. Therefore, I commend the Committee for recognizing the importance of this issue and holding a hearing on this legislation.

The establishment of a National Center for Research on Minority Health and Health Disparities may assist in the coordination of minority health research and the delivery of health services in a culturally appropriate manner. A vital aspect of this bill is the comprehensive review and study of all data collection and reporting systems and practices relating to the collection of data on race or ethnicity. It is imperative in examining the effects of race and ethnicity on health care access and outcomes to collect information on subgroups within specific minority populations. When targeting prevention as well as treatment efforts, different methods and approaches may be needed to address the distinct needs of certain subpopulations. I can best describe this through example.

In New Jersey, we have had a very successful HIV surveillance system in place since 1992. Prior to November 1991, only persons diagnosed with full-blown AIDS were reported to the State Health Department. As you know, an AIDS diagnosis and the concomitant damage to an individual's immune system may reflect an infection that occurred 10 to 15 years earlier. AIDS is truly the end stage of what we refer to as HIV disease. Since we began collecting information on persons diagnosed with HIV infection, we have been able to obtain data on persons more recently infected with HIV. We have been looking at the "front end" of the epidemic for over eight years. This has enabled us, in collaboration with the New Jersey HIV Prevention Community Planning Group, to better prioritize and target our prevention efforts throughout the State. We have been able to fund programs that may not have received prevention funds without the kind of data analysis conducted on HIV disease. We have found that among teens and young adults, aged 13-24, more than one-half of the persons living with HIV disease are females—the only age group where females outnumber males. Additionally, 84% of this population are Hispanic or African American. If we were just looking at AIDS case data, we would not be aware of this fact, and would only see that 61% of all people ever diagnosed with AIDS in that age group were males. The HIV information has shown us that teenage girls and young women, especially those who are African American or Hispanic, are being infected and living with HIV in larger numbers than males. This is a significant



change from the first decade of the epidemic, and is critical information for targeting our prevention efforts to young people.

HIV surveillance has also given us the opportunity to determine the implementation and effectiveness of public health service recommendations for preventing perinatal HIV transmission, opportunistic infections, and AIDS defining illnesses. The HIV disease data can also be used to assess potential short-term and long-term adverse outcomes related to perinatal exposure to antiretroviral agents. These effects include birth defects, toxic reactions, and tumor development. When we know a great deal of information about people living with HIV infection, we can allocate prevention, counseling, treatment and other resources where the need is greatest. This information has also enabled us to determine that the decline in deaths among those with HIV/AIDS has not been uniform across all racial and ethnic groups. For example, there has been a 73% decline in deaths among AIDS patients in New Jersey between 1995 and 1999. However, the decline among whites was 83%, among Hispanics was 72%, and among African Americans was 68%.

Even with this HIV/AIDS surveillance system, which is a model program nationally, our efforts would be greatly enhanced if we could include more information on minority subgroups. When an epidemic affects minorities as disproportionately as the HIV epidemic has done, it is too easy to simply say we need to have certain programs for Hispanics and certain programs for African Americans, and leave it at that level. If we want to make a significant impact, we need to target subgroups that may differ on critical characteristics or cultural norms. If we could look at more specific subpopulation data, we would be better able to determine and evaluate prevention efforts within specific communities. We would also have more information regarding treatment/support system needs within subgroups. Using methods and approaches that are appropriate to different subgroup populations will recognize the cultural differences that exist in the larger community.

Because of the data systems in place in most hospitals and provider offices, we are limited to the general category of Hispanic if we want to look at data specifically for Latinos. Institutionalized data collection systems need to systematically collect information on minority subpopulations. Federal standards for the uniform collection of race and ethnic information must lead the way for the reporting of this data. Currently, we can only obtain this level of detail by directly interviewing patients or clients. Since it would be impossible for us to conduct interviews with all persons reported with HIV infection, we are limited in our ability to obtain this data except for certain special studies.

I would like to reiterate our support for this legislation and the establishment of a National Center for Research on Minority Health and Health Disparities. I also urge as a priority the examination of all collection and reporting systems relating to data on race and ethnicity. Our efforts, as we enter the third decade of our battle against HIV disease, would be greatly enhanced with more thorough information on minority subpopulations.

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PREPARED STATEMENT OF THOMAS LIBERTI, CHIEF, BUREAU OF HIV/AIDS, FLORIDA  
DEPARTMENT OF HEALTH

My name is Thomas Liberti. I am Chief of the Bureau of HIV/AIDS, Florida Department of Health. I would like to thank the Chairman and the members of the Subcommittee on Health and Environment for inviting me to submit written testimony on the impact of HIV/AIDS on the health status of racial and ethnic minorities in Florida and Florida's response to this challenge.

Florida has 5.5% of the U.S. population, but 10.2% of the 724,656 cumulative AIDS cases reported in the U.S. through 1999. Florida's population of more than 15 million people is racially and ethnically diverse: 73% are white, 13% are black, 12% are Hispanic, 1% are Asian/Pacific Islander and less than 1% are American Indian. Minority populations in Florida, particularly blacks, have been disproportionately affected by HIV/AIDS, and the numbers of HIV/AIDS cases in their ranks have been exacerbated by special issues and barriers associated with HIV prevention, early intervention and patient care. With regard to HIV/AIDS, the racial and ethnic disparities are quite alarming.

In Florida, blacks have historically had relatively poor access to quality health care. They tend to have problems associated with poverty, poor schools, inadequate social services, limited housing, few job opportunities and lack of insurance that impede HIV/AIDS prevention initiatives and access to HIV/AIDS health care. These issues are further complicated by patterns of substance abuse and sexually transmitted diseases in the black community. In addition, many blacks have a basic lack of trust in the health care system. The stigma associated with HIV/AIDS continues



to affect the black community, and blacks often seek help only when they are acutely ill. Prevention and treatment programs in the black community must be built around sound, culturally appropriate, working relationships that establish and foster trust. The most effective programs for blacks will be those that are driven by members of the black community. Such programs must address critical issues of late access to HIV diagnostic and treatment services, which are consistently reflected in HIV/AIDS trends:

- Compared with the U.S., Florida's AIDS cases are more likely to be black (46% versus 37% of total cases), female (21% versus 16%) and heterosexual (16% versus 10%).
- While blacks comprise 13% of Florida's population, they account for 46% of the 75,694 AIDS cases and 60% of the 14,765 HIV cases reported in the state through 1999. (HIV infection reporting was implemented in July 1997.)
- In 1999, blacks accounted for 47% of AIDS cases in men and 73% of those in women.
- In 1999, the AIDS incidence rate per 100,000 among blacks was 238.3, almost 12 times higher than that for whites (20.4).
- In 1999, blacks accounted for 51% of HIV cases in men and 75% of those in women.
- It is estimated that more than 35,000 blacks in Florida are currently living with HIV infection.
- An estimated 1 in 50 blacks are HIV-infected, compared to 1 in 127 Hispanics and 1 in 286 whites.
- Through 1999, among blacks with a reported risk factor for AIDS, 22% were men who have sex with men, 33% were injection drug users, 5% were both men who have sex with men and injection drug users, and 38% were those who acquired HIV through heterosexual contact.
- Among childbearing women in Florida, blacks are at least 10 times more likely than whites to be HIV-infected.
- 81% of Florida's 1,374 pediatric AIDS cases and 81% of Florida's 142 pediatric HIV cases are black.
- Black women who are heterosexually infected with HIV are the fastest growing group of infected persons.
- HIV/AIDS is the leading cause of death for both male and female blacks aged 25 to 44 years.
- In 1999, blacks accounted for 58% of all HIV/AIDS deaths.
- The HIV/AIDS death rate per 100,000 population in 1994 was 5.5 times higher for blacks than for whites; in 1999, the rate increased to 10.9 times higher for blacks than for whites.

In Florida, Hispanic communities are extremely diverse.

Members of these communities include any persons whose ancestry can be traced to Cuba, Puerto Rico, Mexico, Central or South America, or other Spanish cultures or countries of origin regardless of race. During the past 20 years, the Hispanic population has emerged as one of the fastest growing segments of Florida's population. Many Hispanics are faced with problems of unemployment, inadequate housing, poor access to health care, and language barriers.

- Hispanics account for 12% of Florida's population, but 15% of the cumulative AIDS cases and 14% of the cumulative HIV cases reported through 1999.
- In 1999, the AIDS incidence rate per 100,000 population among Hispanics was 63.8, three times higher than that for whites (20.4).
- It is estimated that more than 12,000 Hispanics in Florida are currently living with HIV infection.
- Through 1999, among Hispanics with a reported risk factor for AIDS, 61% were men who have sex with men, 18% were injection drug users, 5% were both men who have sex with men and injection drug users, and 14% were those who acquired HIV through heterosexual contact.
- Male-to-male sexual contact is the predominant mode of HIV transmission among Cubans, while injection drug use predominates among Puerto Ricans.
- HIV/AIDS is the third leading cause of death among Hispanics aged 25-44 years.
- In 1999, Hispanics accounted for 12% of all HIV/AIDS deaths.
- From 1994 through 1999, the HIV/AIDS death rate per 100,000 population has consistently been more than two times higher than that for whites.

Asian/Pacific Islanders and American Indians comprise 1.4% of Florida's population. Members of these communities differ widely in language used, cultures and times of immigration to Florida. Combined, they account for less than 1% of the cumulative AIDS cases reported through 1999. In 1999, their AIDS incidence rate per 100,000 population was 26.0; however, this rate is based on a total of only 17 cases



reported in 1999. These low numbers may reflect under-counting and data collection issues.

(Supplemental, supporting data concerning HIV/AIDS and minorities in Florida are respectfully attached to this testimony for the Committee's consideration.)

Eliminating disparities in health outcomes is a major priority for the Florida Department of Health and Governor Jeb Bush. Under the leadership of Department of Health Secretary Robert G. Brooks, M.D., the department has identified the following six major areas of health disparities in culturally and ethnically diverse communities in the state: maternal/ infant mortality, vaccinations, HIV/AIDS, diabetes, chronic cardiovascular diseases, and cancer. In response to this crisis, the 2000 Legislature passed and funded an act entitled, "Reducing Racial and Ethnic Health Disparities: Closing the Gap," to improve racial and ethnic health outcomes.

In addition, the Florida Department of Health has made numerous efforts to address the racial and ethnic disparities in HIV/AIDS health outcomes through community-based, culturally sensitive approaches. These efforts include working with minority, community-based organizations to implement culturally sensitive HIV prevention and treatment programs; facilitating efforts of black clergy and their congregations to mobilize risk-reduction education and supportive attitudes from within the community; and continuing to work with legislative and other community leaders to assure enhanced resources in areas of greatest unmet need.

In September 1999, Secretary Brooks appointed 23 members to Florida's Minority HIV/AIDS Task Force. The task force is composed of representatives from various groups, including persons infected with HIV or AIDS, minority community-based support organizations, minority treatment providers, the religious community, and the Department of Health. The creation of the task force was mandated by HB 2125, which was passed during the 1999 Legislative Session, largely due to the efforts of the Legislative Black Caucus.

The Department of Health strongly encouraged the creation of the task force as a means of addressing the disproportionate impact of HIV/AIDS on minorities. The task force has been compiling testimony at public meetings throughout the state to submit a report of its findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives by February 1, 2001. This report will include:

- specific strategies for reducing the risk of HIV and AIDS in the state's minority communities;
- a plan for establishing mentor programs and exchanging information and ideas among minority community-based organizations that provide HIV and AIDS prevention services;
- the needs of prevention and treatment programs within communities and the resources that are available within minority communities;
- specific strategies for ensuring that minority persons who are at risk of HIV and AIDS infection seek testing;
- specific strategies for ensuring that persons who test positive for HIV or AIDS are provided with access to treatment and secondary prevention services;
- specific strategies to help reduce or eliminate high-risk behaviors in persons who test negative but continue to practice high-risk behaviors; and
- a plan to evaluate the implementation of the recommendations of the task force.

In November 1999, the Department of Health's Office of Equal Opportunity and Minority Health hosted state and national leaders from government, health care and the minority community at the Inaugural Interagency Minority Health Symposium in Orlando. The symposium, entitled "Joining Hands, Gathering Solutions," focused on the collaborative roles state agencies can play in eliminating HIV/AIDS disparities and other health disparities among the state's minority communities. During the symposium, presenters provided compelling data and information concerning these issues and discussed access and operational challenges and solutions. Panels composed of state agency representatives convened to discuss existing and natural organizational partnerships and to explore ways to maximize the influence of those partnerships in advancing the health of all Floridians.

In January 2000, the Department of Health, Bureau of HIV/AIDS conducted the Florida Black Leadership Conference on HIV/AIDS in Fort Lauderdale. This two-day conference brought together community leaders; representatives of faith communities and community based organizations; business leaders; people living with HIV or AIDS; political leaders; and other partners in the black community. The goal of the conference was to develop innovative ways to reinforce the black community's primary and secondary HIV prevention efforts through educational plenary sessions and interactive workshops. The diversity of the participants and unique structure of the conference provided opportunities for the Department of Health to compile recommendations to help guide future HIV/AIDS programs and policies.



Other initiatives include the following:

- Establishing the Florida HIV/AIDS Minority Network, a venue for minority community-based organizations and faith-based organizations throughout the state to share information, ideas, provide peer mentoring and receive expert technical assistance on infrastructure development and capacity building.
- Conducting “Church as a Change Agent Workshops,” one-day workshops held with pastors and other leaders in the faith communities, inviting the black church to partner with the Florida Department of Health on HIV/AIDS prevention initiatives.
- Creating regional minority HIV/AIDS coordinator positions to spearhead local minority initiatives and work cooperatively with existing establishments to strengthen minority HIV prevention and care organizations.
- Targeting HIV/AIDS funding to minority communities through 40 prevention contracts.
- Implementing the Targeted Outreach to Pregnant Women Act to link at-risk women to services.
- Providing intensive outreach to bring more minorities into programs such as the AIDS Drug Assistance Program, the AIDS Insurance Continuation Program and Housing Opportunities for Persons with AIDS.
- Ensuring that minority HIV/AIDS patients have expanded access to outpatient medical care, pharmaceuticals, dental services, and case management.
- Partnering with alcohol, drug abuse and mental health programs to develop and implement HIV/AIDS prevention projects statewide.
- Collaborating with the Department of Corrections to conduct peer education projects at three large correctional facilities.

The Florida Department of Health recognizes and appreciates the efforts of the Subcommittee on Health and Environment, the Congressional Black Caucus and the President’s race initiative to address the root causes of racial/ethnic disparities concerning HIV/AIDS. We are encouraged that our nation’s leaders have entered into such meaningful partnerships with the states, through which culturally sensitive HIV/AIDS prevention and patient care programs can be further developed and implemented to close the racial/ethnic gap.

I would like to thank you, once again, for the opportunity to provide testimony on the impact of HIV/AIDS on minorities in Florida, and our response to the challenges of this devastating epidemic.





*AIDS Cases in  
Racial/Ethnic  
Minorities  
Florida*



# **AIDS Cases in Adult and Adolescents by Exposure Category and Race/Ethnicity Florida, Reported through 1999**

Exposure category	Asian/Pacific Islander		American Indian	
	Number	%	Number	%
<b>Men who have sex with men (MSM)</b>	<b>65</b>	<b>48%</b>	<b>28</b>	<b>48%</b>
Injection drug use (IDU)	11	8%	10	17%
MSM and IDU	1	1%	6	10%
Heterosexual contact	19	14%	3	5%
Other/not identified*	39	29%	11	19%
<b>Total</b>	<b>135</b>	<b>100%</b>	<b>58</b>	<b>100%</b>

AIDS Surveillance, Data as of 04/00  
Data Source: Department of Health HARS Database





# **AIDS Cases in Adult and Adolescents by Exposure Category and Race/Ethnicity Florida, Reported through 1999**

Exposure category	Black, not Hispanic		Hispanic	
	Number	%	Number	%
Men who have sex with men (MSM)	5,103	15%	5,733	50%
Injection drug use (IDU)	7,832	24%	1,678	15%
MSM and IDU	1,254	4%	474	4%
Heterosexual contact	8,797	26%	1,344	12%
Other/not identified*	10,331	31%	2136	19%
Total	33,317	100%	11,365	100%

AIDS Surveillance, Data as of 04/00  
Data Source: Department of Health HARS Database



## AIDS in Blacks and Hispanics

Of the 75,694 AIDS cases reported in Florida through 1999, Blacks and Hispanics accounted for

61% of total cases

54% of adult male cases

82% of adult female cases

83% of heterosexual cases\*

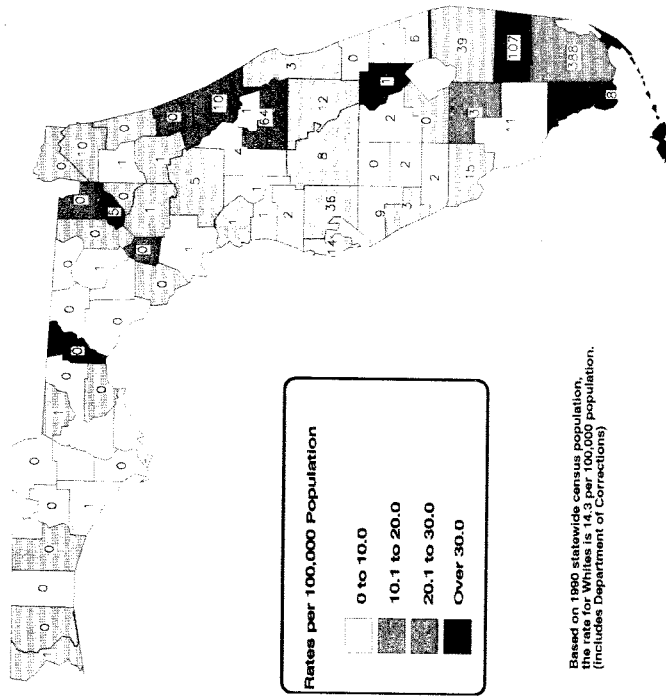
89% of cases among children

Of AIDS cases reported in 1999, 70% were among Black and Hispanic adults and adolescents.

\* Heterosexual injection drug users and persons with heterosexually acquired HIV

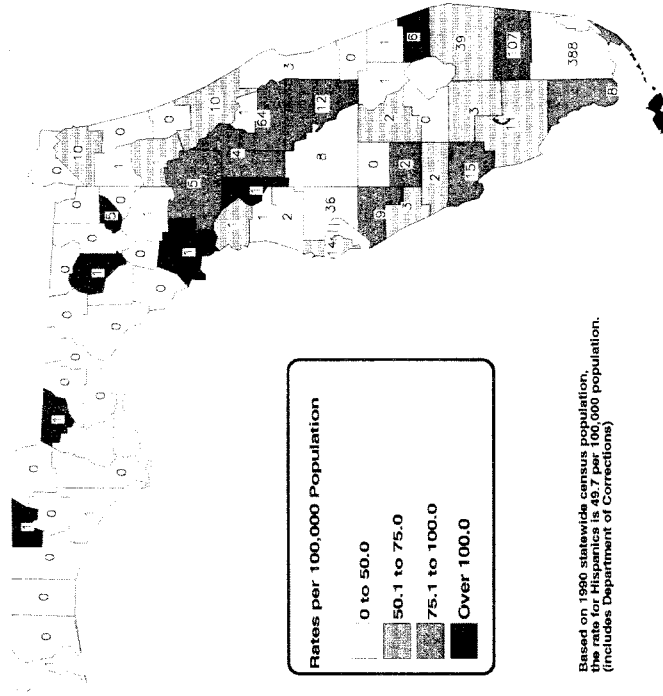


# Reported AIDS Cases and Rates per 100,000 Population Among Whites, by County of Residence, 1999



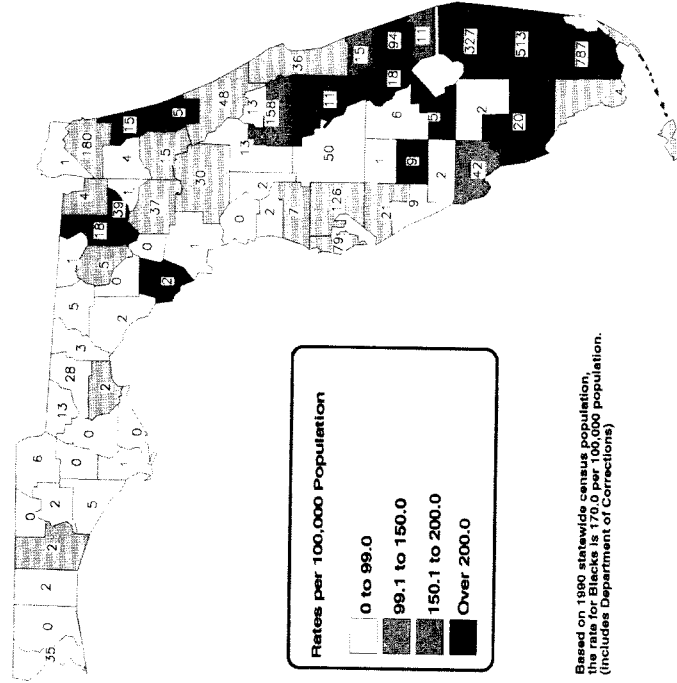


# **Reported AIDS Cases and Rates per 100,000 Population Among Hispanics, by County of Residence, 1999**



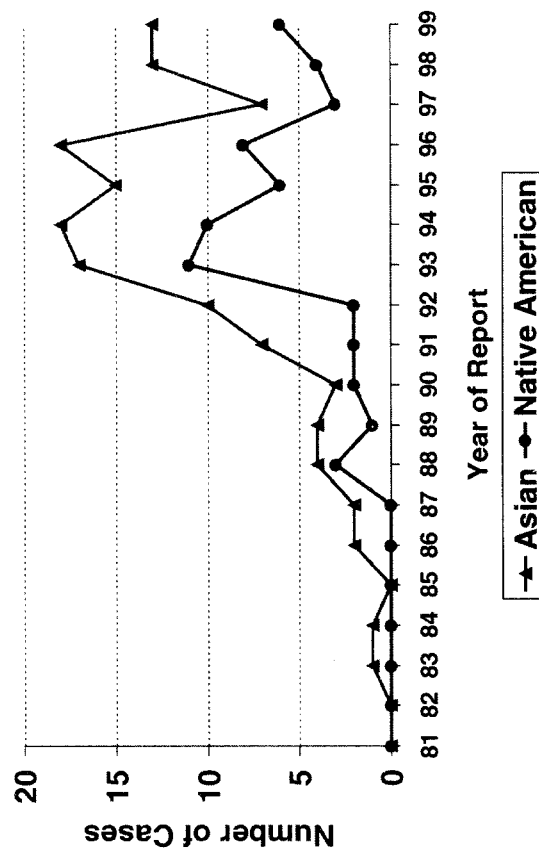


# Reported AIDS Cases and Rates per 100,000 Population Among Blacks, by County of Residence, 1999





**AIDS Cases Among  
Asians and Native Americans  
by Year of Report Florida, 1981-1999**





**Number and Percent of Resident HIV/AIDS Deaths  
By Race/Ethnicity and Sex, Florida, 1994 - 1999\***

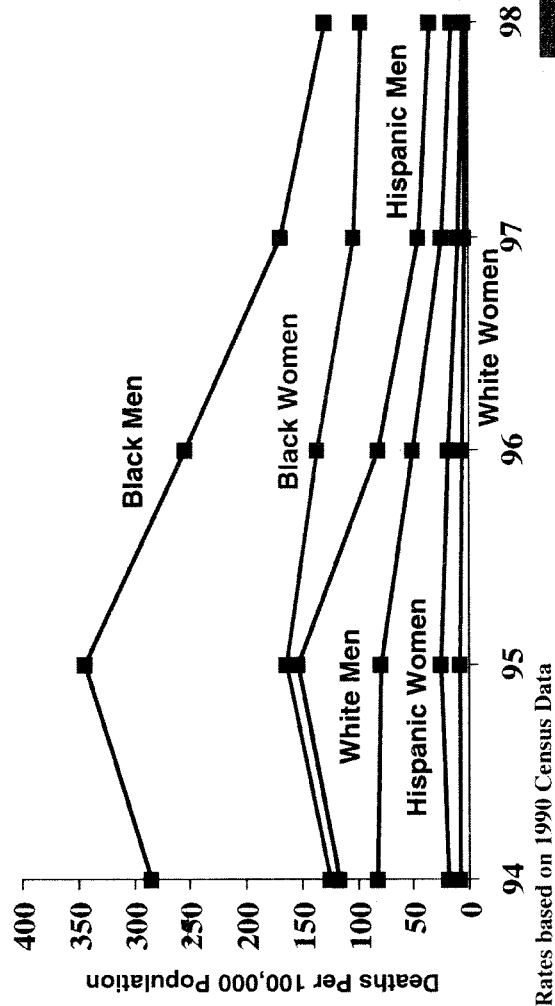
Race/Ethnicity	1994		1995		1996		1997		1998		1999*	
	No.	% of total	No.	% of total	No.	% of total	No.	% of total	No.	% of total	No.	% of total
White Male	1,612	39%	1,543	36%	999	32%	509	27%	340	22%	413	25%
White Female	161	4%	153	4%	131	4%	74	4%	62	4%	70	4%
Black Male	1,189	29%	1,324	31%	1,012	33%	680	36%	565	37%	567	35%
Black Female	557	13%	657	15%	533	17%	396	21%	410	27%	376	23%
Hispanic Male	536	13%	558	13%	347	11%	180	10%	137	9%	163	10%
Hispanic Female	82	2%	93	2%	67	2%	37	2%	29	2%	36	2%
Other**	5	0%	8	0%	4	0%	3	0%	4	0%	6	0%
<b>TOTAL</b>	<b>4,142</b>	<b>100%</b>	<b>4,336</b>	<b>100%</b>	<b>3,093</b>	<b>100%</b>	<b>1,879</b>	<b>100%</b>	<b>1,547</b>	<b>100%</b>	<b>1,831</b>	<b>100%</b>

\* 1999 data are provisional, and unadjusted for the change in coding of HIV deaths, effective Jan. 1999.

\*\*Other include persons of other/unknown race and non-Hispanic origin or sex.  
Florida Department of Health, Office of Vital Statistics and Bureau of HIV/AIDS

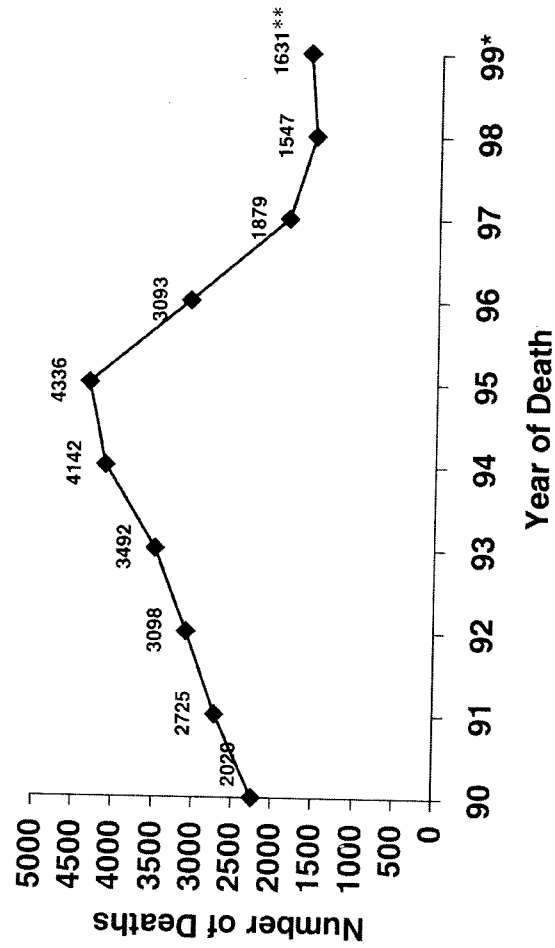


# Death Rates for HIV Infection in Persons Aged 25-44 Years, by Sex and Race, by Year Florida, 1994-1998





## Resident HIV/AIDS Deaths By Year, Florida, 1990 - 1999\*



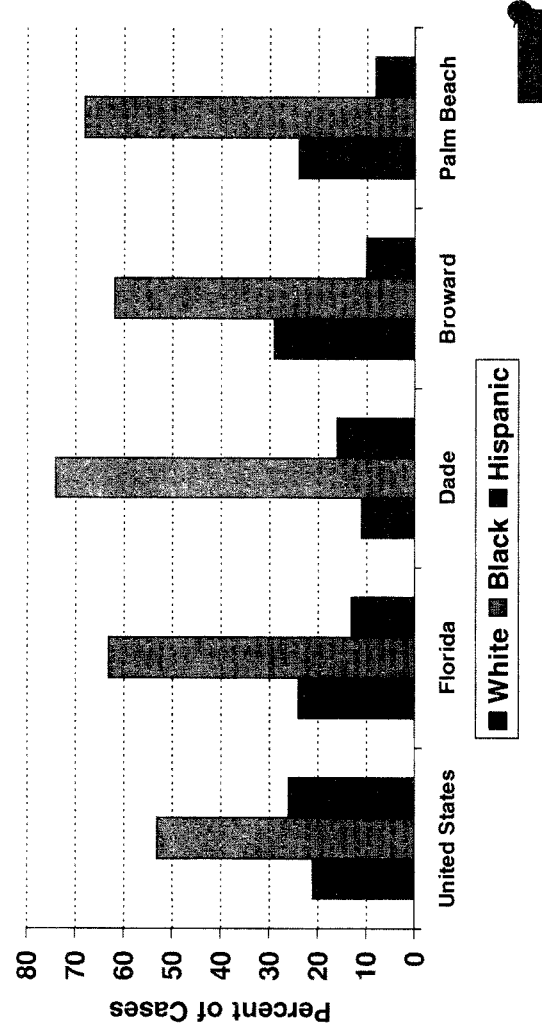
Source: Office of Vital Statistics, Death Certificates

\*1999 death data provisional.

\*\*Adjusted provisional number of deaths in 1999 is approximately 1,553 (1,631/1.05), which adjusts for the change in coding of HIV deaths, effective January 1999.

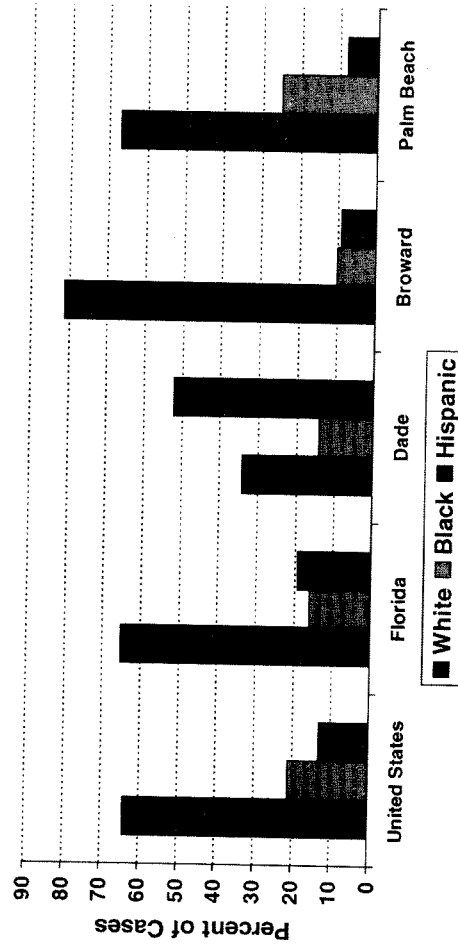


# **Cumulative Adult AIDS Cases Through 1999** **Among Injecting Drug Users** **by Race/Ethnicity and Selected Area**



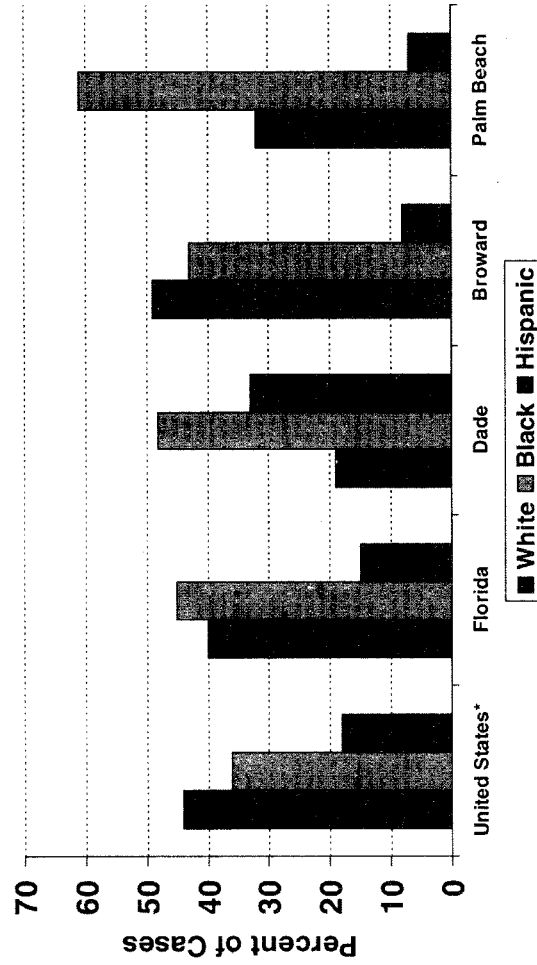


# Cumulative Adult AIDS Cases Through 1999 Among Men Who Have Sex with Men, by Race/Ethnicity and Selected Reporting Area





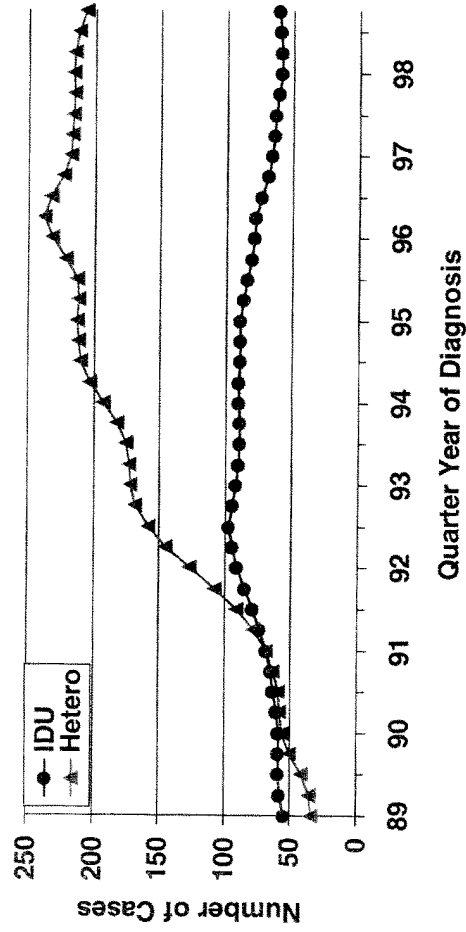
# Cumulative Adult AIDS Cases Through 1999 by Race/Ethnicity and Selected Area



\*United States data as of 12/31/98



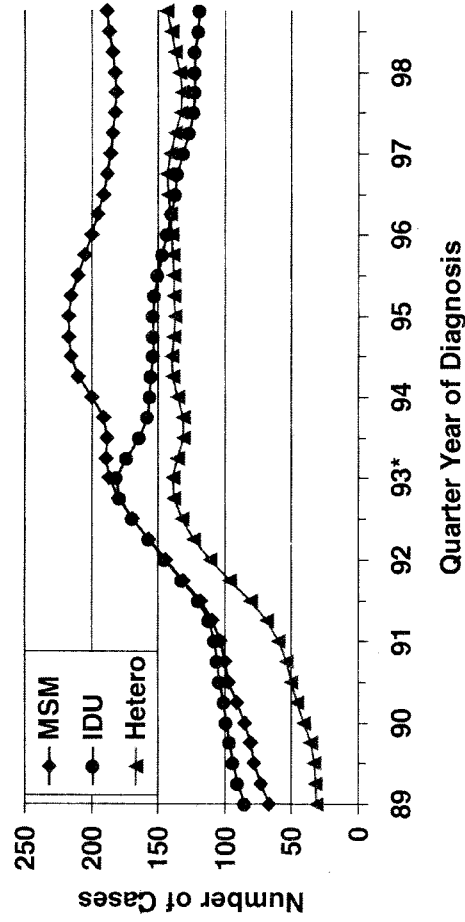
# Florida AIDS Cases Among Adult Black Females By Mode of Exposure Adjusted\* Quarterly Incidence, 1989 - 1998



\*Adjustments have been made to account for reporting delays and the redistribution of NIRs.



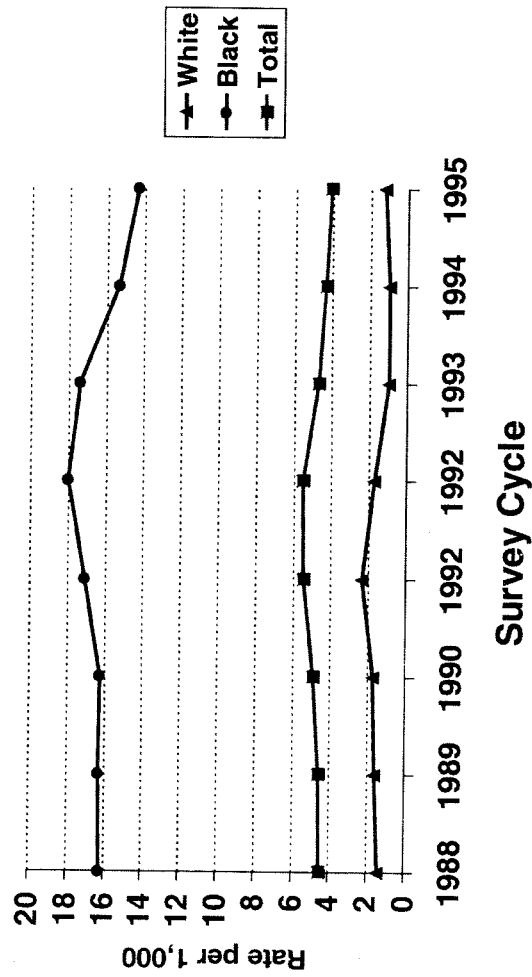
# Florida AIDS Cases Among Adult Black Males By Mode of Exposure Adjusted\* Quarterly Incidence, 1989 - 1998



\*Adjustments have been made to account for reporting delays and the redistribution of NIRs.



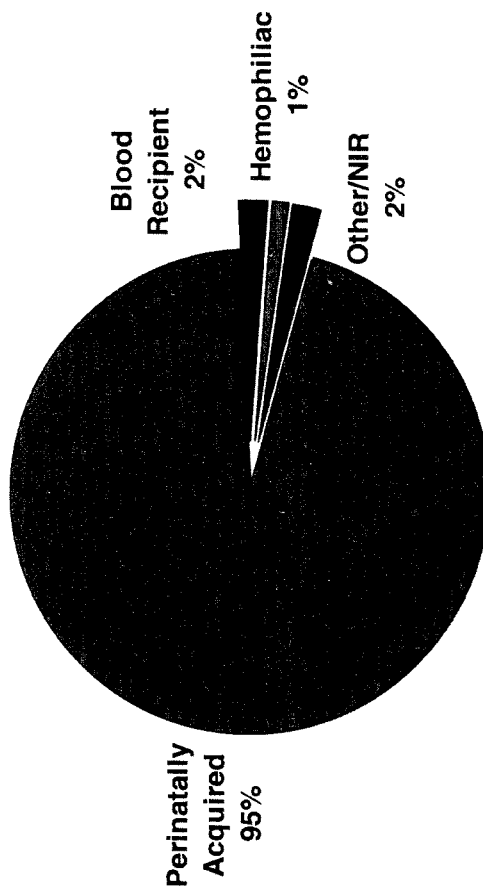
# HIV Seroprevalence among Childbearing Women by Survey Cycle and Mother's Race Florida, 1988-1995



\*Number Positive/Number Tested x 1,000  
Survey Cycles are October through March, except for the last cycle which was 10/95-12/95



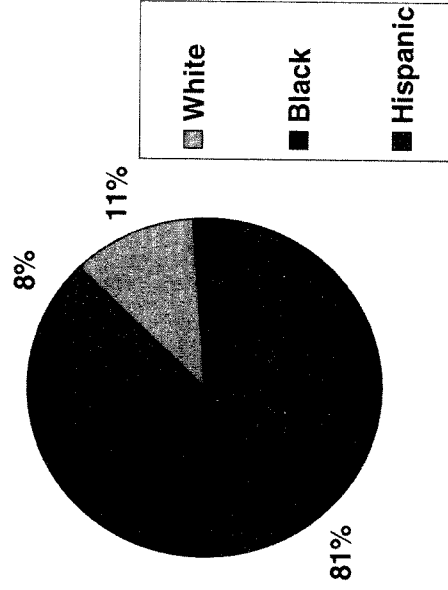
**Cumulative Pediatric (<13 yr.)  
AIDS Cases By Exposure Category  
Florida, Reported through 1999 (N=1,374 )**



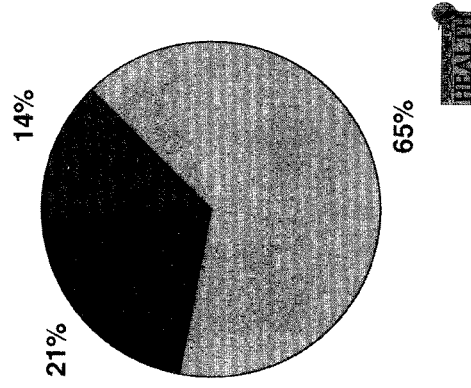


# Florida

**Pediatric (Ages <13) AIDS Cases  
By Race/Ethnicity  
Reported through 1999 (N = 1,374)**



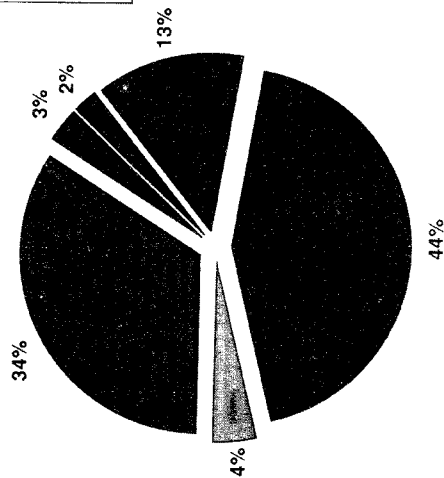
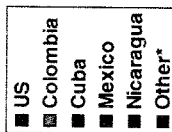
**1990 Population  
By Race/Ethnicity  
(Ages <13)  
(N = 2,138,726)**



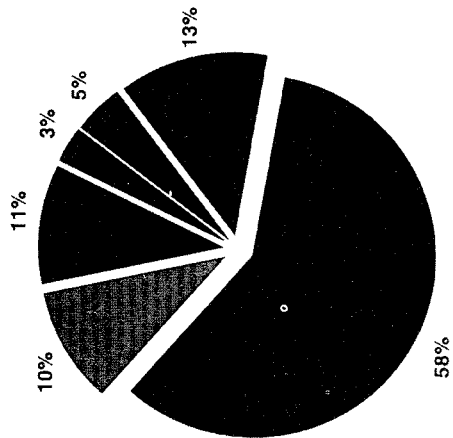


# Total Hispanic Adult AIDS and HIV Cases By Country of Birth, Florida, Data through 1999

**AIDS (N = 6,349)**



**HIV (N = 919)**

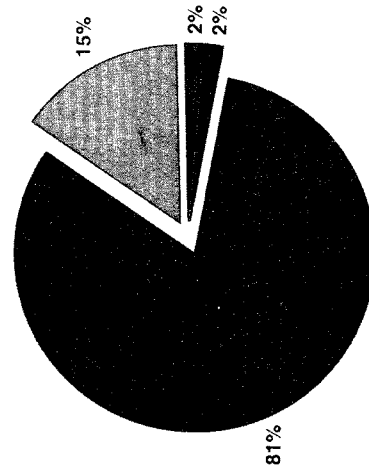
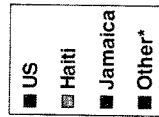


\*Other includes Puerto Rico, Guatemala, Honduras, and other Hispanic countries.

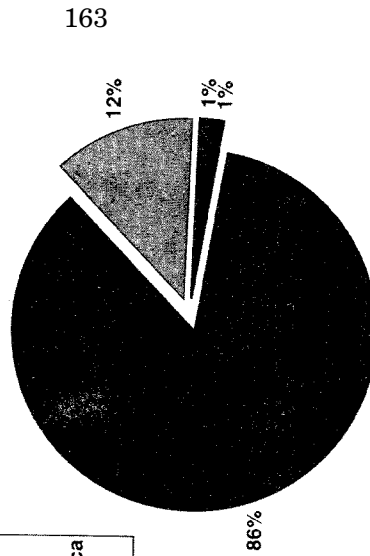


# **Total Black Adult AIDS and HIV Cases** **By Country of Birth, Florida, Data through 1999**

**AIDS (N = 33,317)**



**HIV (N = 8,482)**



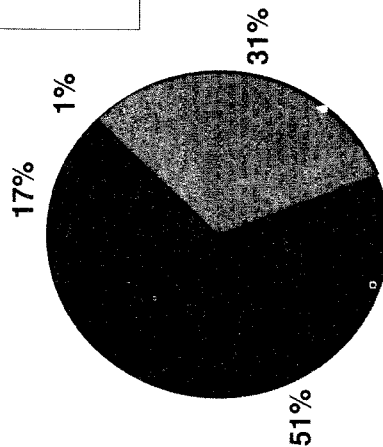
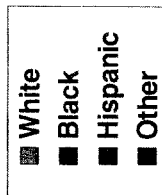
\*Other includes 23 countries with less than one percent of total in each country.



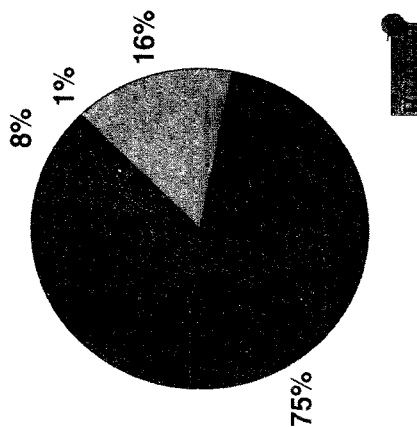


# Reported Adult HIV Cases By Sex and Race Ethnicity, Florida, 1999

**Males**  
N = (3,760)



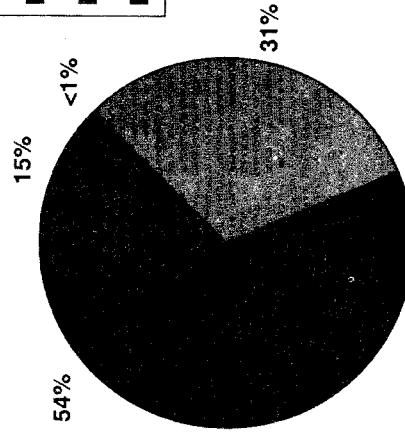
**Females**  
N = (2,314)



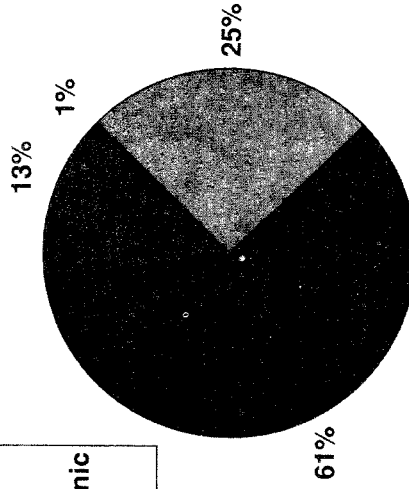


# FLORIDA

Adult AIDS Cases by  
Race/Ethnicity  
1999 (N=5,366)



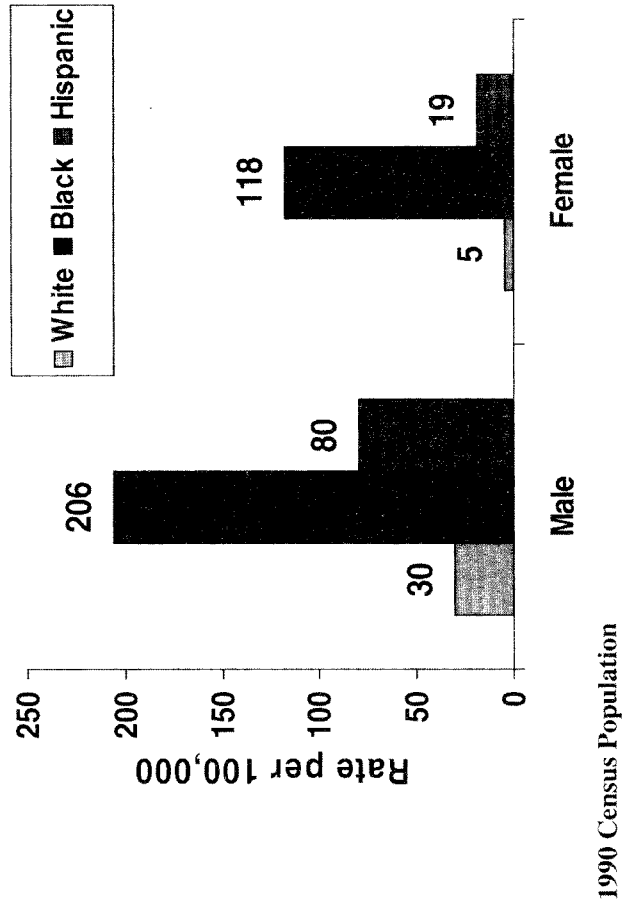
Adult HIV Cases  
Race/Ethnicity  
1999 (N=6,074)



1990 Census Pop = 74% White, 13% Black and 12% Hispanic



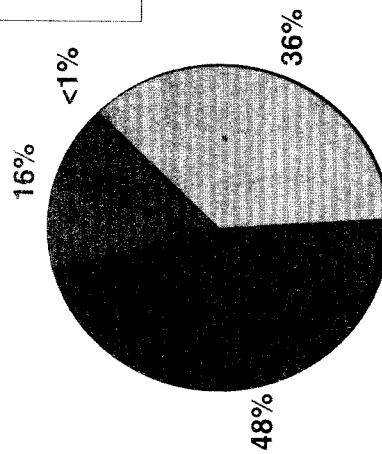
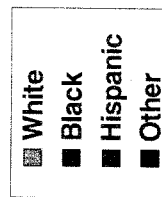
# **Reported AIDS Case Rates per 100,000 Population By Sex and Race/Ethnicity, Florida, 1999**



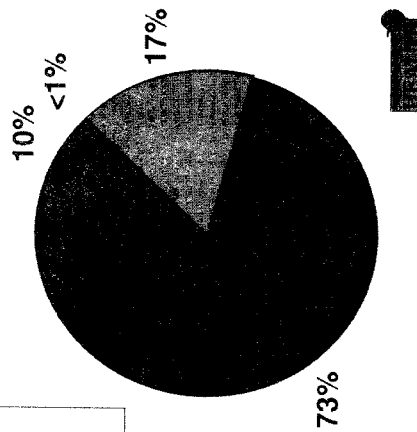


# Reported Adult AIDS Cases By Sex and Race Ethnicity, Florida, 1999

**Males**  
**N = (3,896)**

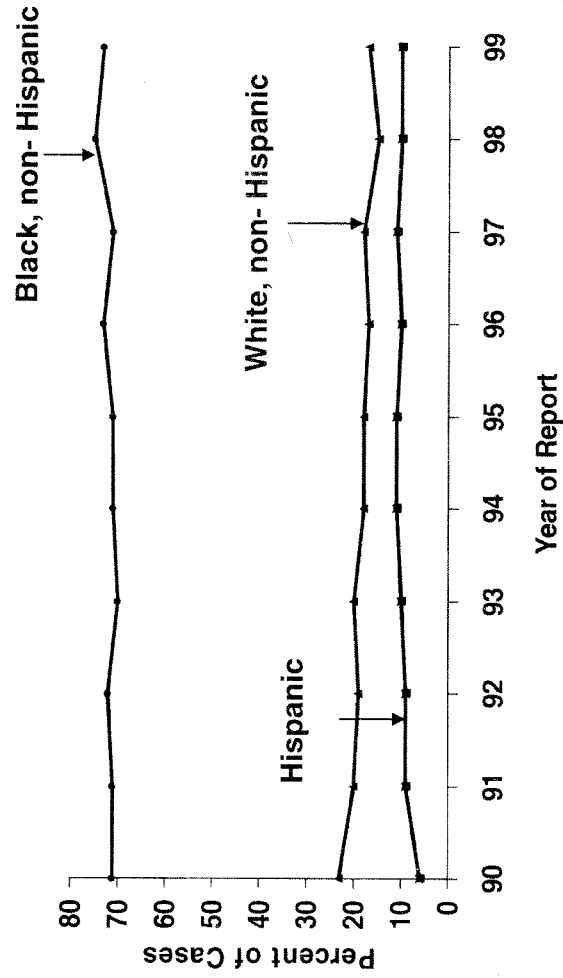


**Females**  
**N = (1,470)**



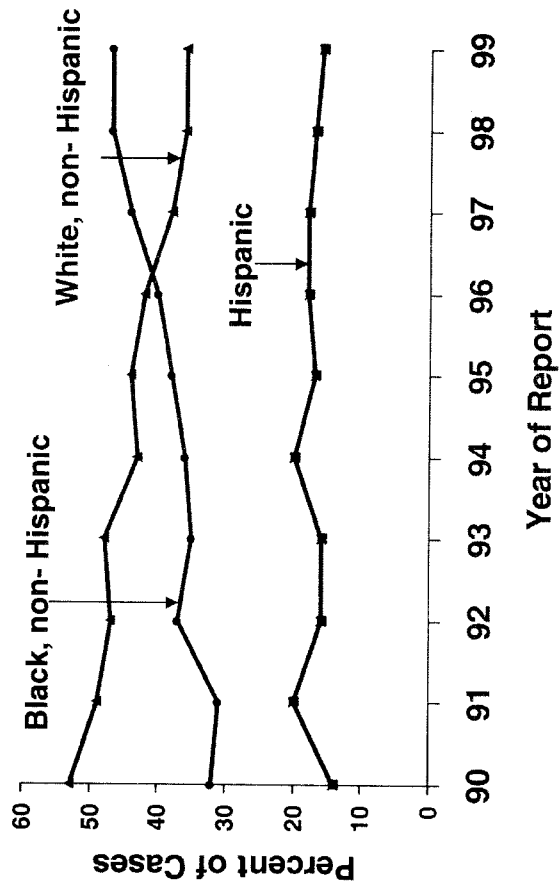


# **Percent of Adult Female AIDS Cases By Race/Ethnicity and Year of Report Florida, 1990-1999**



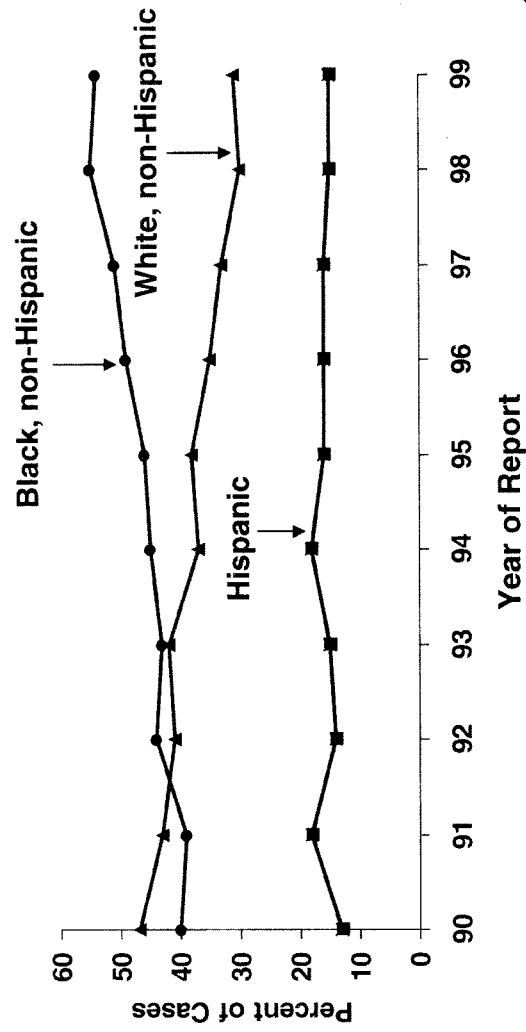


**Percent of Adult Male AIDS Cases  
By Race/Ethnicity and Year of Report  
Florida, 1990-1999**





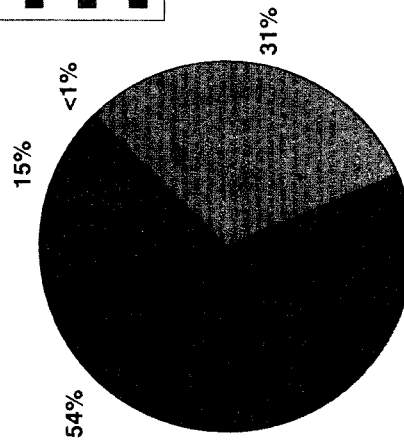
### Adult AIDS Cases by Race/Ethnicity and Year of Report, Florida, 1990-1999



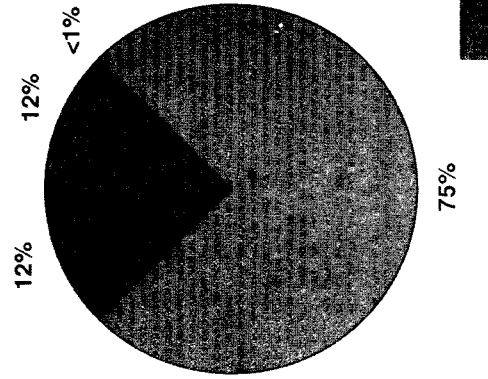


# FLORIDA

**Adult AIDS Cases  
By Race/Ethnicity  
1999 (N=5,366)**



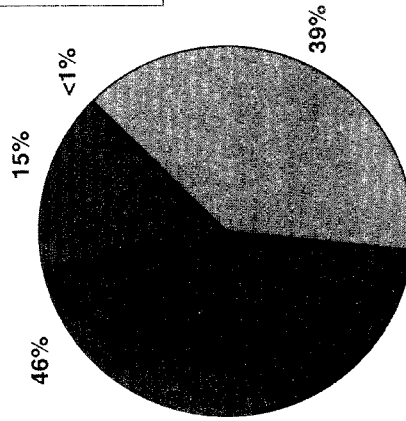
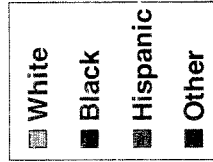
**1990 Adult Population  
By Race/Ethnicity  
(N=10,799,200)**



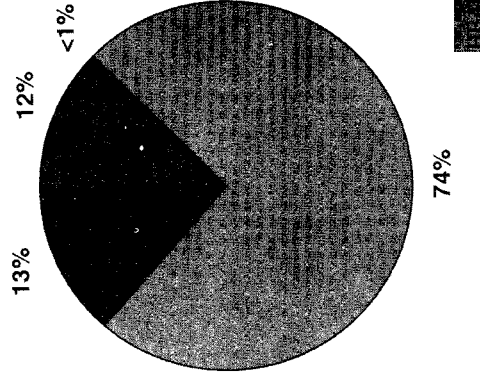


# FLORIDA

**Cumulative AIDS Cases  
By Race/Ethnicity  
Through 1999 (N=75,694)**



**1990 Population by  
By Race/Ethnicity  
(N=12,937,926)**





June 16, 2000

MICHAEL BILIRAKIS, *Chairman*  
*Subcommittee on Health and Environment*  
*U.S. House of Representatives*  
*Committee on Commerce*  
*Room 2125, Rayburn House Office Building*  
*Washington, DC 20515-6115*

DEAR MR. BILIRAKIS: As requested in your letter of June 2, 2000, I am providing supplemental information to my testimony of May 11. I have restated each question, and followed it with my response.

*Question:* The Commonwealth of Virginia reports both cases of HIV and AIDS. Does reporting the full scope of HIV infection and not just the end stage, AIDS, provide better opportunities to address prevention and care and any disparities that may exist?

*Response:* HIV reporting provides data for identifying populations in which HIV has been newly diagnosed, whereas AIDS reporting usually identifies individuals infected years ago. In 1999 in Virginia, women comprised 31% of reported HIV cases, but just 23% of reported AIDS cases. While the 1999 racial breakdown for reported African-American HIV cases (69%) compared to AIDS cases (66%) does not now show a large difference, the trend to increasing proportions in minority populations was identified several years earlier because Virginia had HIV reporting.

Age differences are also seen between AIDS and HIV cases. Of 52,690 HIV infections diagnosed from January 1994 through June 1997 in 25 states that conducted name-based surveillance, 14% of the cases occurred in persons aged 13-24 years. In comparison, only 3% of AIDS cases occurred within this age group in the same time period. Thus, AIDS case surveillance alone does not accurately reflect the extent of the HIV epidemic among adolescents and young adults.

Required HIV reporting therefore catches changing demographics of cases far earlier than AIDS reporting alone can do. This allows earlier determination of populations at risk and behavioral risk factors, and earlier targeted resource allocation to address recognized changes.

Since 1996, HIV treatment utilizing a combination of anti-retroviral medications has prevented many individuals with HIV infection from progressing to AIDS. AIDS reporting alone would never capture these individuals. Therefore, states that have documented cases of both AIDS and HIV infection provide a more reliable and useful estimate of the resources needed for patient care and services than AIDS prevalence alone.

*Question:* Surgeon General Satcher testified that he supports the CDC recommendations made last December to move states to HIV name reporting, while the Commonwealth of Virginia has conducted HIV name reporting and partner notification for over a decade. Has the minority community (or any community) voiced objections to these practices? Has there ever been a breach of patient confidentiality that has resulted from either of these practices?

*Response:* There has never been a breach of confidentiality, and I am confident in the ability of staff of the Division of HIV/STD to handle information professionally. Periodically, the minority community has raised questions in public meetings, forums, and presentations addressing minority health and AIDS issues. Concerns have typically focused upon misconceptions regarding both the name-based reporting and partner notification processes. These questions have been addressed by providing information about the Division of HIV/STD's policies regarding confidentiality. All employees are required to review and sign confidentiality statements outlining the procedures to be followed when processing all HIV/STD epidemiological documents.

Presentations describing the Virginia Department of Health's (VDH) commitment to confidential partner notification, along with an explanation of methods used to notify individuals, have been helpful in alleviating the public's concerns and clearing up misconceptions. In addition, VDH speakers review HIV-related legislation that outlines confidentiality requirements and penalties for non-adherence, in order to stress the legal protections provided by existing policies and procedures. The Assistant Attorney General assigned to VDH provides legal guidance and interpretation of policy to localities, further enhancing a consistent approach to these issues.

*Question:* As you know, women and minorities are represented in higher proportions in HIV case reports than in AIDS case reports. Do you believe that changing Ryan White CARE Act funding formulas to take into account HIV cases, rather than just AIDS cases, would be an effective way to better target funding and address some of the health disparities that exist for minorities?



Response: HIV reports present a more accurate picture of the current epidemic than do AIDS reports alone. By monitoring HIV as well as AIDS, Virginia has been able to track the increased percentages of cases that have occurred among minorities and women. If all states reported HIV, then HIV cases could be included in the formula for determining Ryan White funding, and the funds could be more accurately targeted to current needs, earlier intervention and hopefully decreased transmission. More accurate targeting and program planning could assist with addressing some of the health disparities that exist for minorities.

*Question:* Is partner notification a worthwhile prevention tool for HIV? Is it an effective intervention to identifying at-risk individuals and getting them into prevention and care programs?

Response: Partner notification is a very worthwhile tool for HIV and comparable to how public health treats other communicable sexually transmitted diseases. HIV counseling and testing data for Virginia STD clinics for 1986-1998 indicate that 3,658 individuals received HIV testing as a result of being referred as partners of someone with HIV. Of those, 338 (9.2%) tested positive. Cumulatively, about 1% of STD patients has tested positive for HIV; therefore, partner notification clearly assists in identifying higher risk populations and therefore increases the testing and educating of individuals at increased risk. The 338 partners testing positive were also assisted in accessing medical and support care, including the AIDS Drug Assistance Program (ADAP) and other Ryan White services.

*Question:* Is there any evidence to substantiate claims that name-based HIV case reporting discourages individuals from seeking HIV testing or care?

Response: Contrary to the claim that name-based case reporting discourages individuals from seeking HIV testing and care, several studies have shown that name-based reporting does not hinder individuals from seeking testing. Virginia's confidential testing numbers have remained relatively level over the last few years, while anonymous testing has decreased from 10,393 (12% of total tests) in 1992 to 5,518 (7% of total tests) in 1998.

*Question:* Intravenous drug use is a factor for the spread of HIV. Would you say that it should be a priority to develop programs for the treatment of heroin addicts by a new class of heroin-blocking drugs?

Response: Evidence indicates that the new heroin-blocking drugs offer effective alternatives to the current medications available for treating heroin addiction. The Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) is the agency in Virginia that has responsibility for substance abuse treatment, and has indicated that developing programs for heroin addicts with the new heroin-blocking drugs is a priority. DMHMRSAS is currently developing a research protocol to address this issue. I look forward to hearing follow up reports from DMHMRSAS on their efforts and results.

*Question:* The Administration stated in their testimony that "Vietnamese women suffer from cervical cancer at nearly five times the rate of white women." Why is that? Is it a cultural factor linked to the willingness to get screened? Are you doing anything to reach out to this community? Response: Those who work with the Vietnamese community believe that the high incidence of cervical cancer among Vietnamese women is because many have no insurance and are impoverished. They generally do not have an orientation to preventive care. They will seek help for their children, but not for themselves. Since they have not received screening, they are diagnosed at a later stage of the disease. Even when they are symptomatic, they are reluctant to seek help for themselves. For illegal aliens, immigration issues may also present a barrier to seeking care.

The VDH Breast and Cervical Cancer Early Detection Program (BCCEDP) is working with the National Asian Women's Health Organization (NAWHO) to sponsor a pilot training program later in the year entitled "Communicating Across Boundaries." The purpose of this training is to improve the skills and capacity of local and state breast and cervical cancer health care programs and providers in the provision of culturally competent screening services to Asian American women.

The Centers for Disease Control and Prevention, through the BCCEDP, provides funding for screening for breast and cervical cancer throughout the state of Virginia for women 50-64 years of age who are uninsured or underinsured, and at 200% of poverty level or less. Recipients must be legal residents of the United States. The Vietnamese Resettlement Association in Northern Virginia is an administrative provider site for the BCCEDP. Asian women represent one of the minority populations targeted by the BCCEDP for screening services for breast and cervical cancer.

Please let me know if you need any additional information.

Sincerely,

E. ANNE PETERSON, MD, MPH  
State Health Commissioner



June 13, 2000

The Honorable MICHAEL BILIRAKIS  
 Chairman  
 Subcommittee on Health and Environment  
 U.S. House of Representatives  
 Committee on Commerce  
 Room 2125, Rayburn House Office Building  
 Washington, D.C. 20515-6115

DEAR CONGRESSMAN BILIRAKIS: Thank you for your letter of June 2 regarding my testimony before the Subcommittee on Health and Environment on May 11, 2000 on H.R. 3250, the Health Care Fairness Act of 1999. I have addressed the members questions below.

Our study carefully assessed the influence of six patient characteristics or study variables on physician decision making: race, sex, age, type of chest pain, medical history and exercise stress test results. These were the only variables that differed across the 144 cases we presented to the participating physicians (our study subjects). All patients in the study had the same address, the same job description (active or retired), and the same type of insurance (Private or combined private/Medicare). Thus, we did not vary geographic characteristics of the patients in our study.

We recruited our physician sample at two national meetings of physician specialty societies. Thus, participating physicians were drawn from across the country. However, we did not collect information on physician practice location as one of our physician demographic variables.

In comparison to the Wennberg work cited in the letter, we found variation in physician decision making based on patient characteristics in identical settings. The study was not designed to test whether geographical factors have an additional interaction with patient characteristics in physician decision making.

Sincerely,

KEVIN A. SCHULMAN, M.D., *Director*  
*Center for Clinical and Genetic Economics*  
*Duke Clinical Research Institute, Duke University Medical Center*

June 16, 2000

Representative Michael Bilirakis  
 Chairman, Subcommittee on Health and Environment  
 United States House of Representatives  
 2125 Rayburn House Office Building  
 Washington, DC 20515

RE: Follow-up Questions Regarding H.R. 3250

Dear Chairman Bilirakis:

I am responding to the follow-up questions from Subcommittee members regarding H.R. 3250, the Health Care Fairness Act of 1999.

Question 1. Dr. Satcher testified that Vietnamese women suffer from cervical cancer at nearly five times the rate of white women. Why is that? Is it a cultural factor linked to the willingness to get screened? How do you think this reluctance to get screened can be addressed?

Response: Vietnamese women do experience cervical cancer at five times the rate of white women and more than two and half times the rate of any other racial or ethnic group in the United States. Researchers have only recently begun to examine these disease rates, prevention strategies and barriers to care in the Vietnamese community. Routine Pap testing is highly effective in the prevention and early detection of cervical cancer. However, studies consistently report that approximately half of Vietnamese women have never had a Pap test for screening of cervical cancer. (Schulmeister and Lifsey, 1999).



The research to date indicates that culturally appropriate prevention programs provided in the Vietnamese language greatly improve the likelihood that Vietnamese women receive a Pap test. (Phipps, et al., 1999; McPhee, et al., 1997; Yi, 1994). Women who do not have health insurance or do not have a regular physician also are less likely to have had a Pap test. (McPhee, et al., 1997).

To begin to address these barriers, researchers and community-based organizations have focused on developing and implementing culturally sensitive education and prevention programs as well as culturally appropriate and linguistically accessible health services for Vietnamese women. For example, community health workers recruited from the Vietnamese community have been effective in conducting small group sessions to provide education and prevention information and to increase the rates of Pap testing. (Bird, et al., 1998). Similarly, an ethnic media-based community education campaign focused on Vietnamese women also increased rates of Pap testing. (Jenkins, et al. 1999). Assuring continued funding and support for such programs will be vital in increasing rates of Pap testing and decreasing rates of cervical cancer among Vietnamese women.

Question 2. Statistics indicate that 93% of women with cervical cancer had "high-risk" human papillomavirus (HPV), which is recognized as the primary cause or risk factor of cervical cancer. According to the National Cervical Cancer Public Education Campaign, HPV is one of the most common sexually transmitted diseases (STDs) in the United States. Would you agree or disagree with the American Cancer Society's statement that "research shows that condoms cannot protect against infection with HPV"? Would you say that there is a false sense of security that is placed in condoms for viral infections such as HPV? Should Americans be warned that condoms do not protect against HPV?

**Response:** While it is true that condoms do not protect against human papillomavirus (HPV), it is still important to promote the use of condoms to protect against other sexually transmitted diseases. Regular screening, rather than condom use, is the key to early detection and treatment of cervical cancer. We support comprehensive health promotion and disease prevention programs targeted for Asian American and Pacific Islander women that address risks from sexually transmitted diseases in the context of multiple sexual, reproductive, physical and mental health issues as well as culturally appropriate and linguistically accessible health services.

Question 3. What is your opinion of efforts to make health insurance for affordable, such as proposals for expanded tax relief for individuals who do not have job-based coverage and proposals that allow small businesses to pool together to purchase health insurance in groups? Do you think these efforts will help the Asian and Pacific Islander populations secure affordable health coverage?

**Response:** We support universal health coverage for all Americans. Current proposals to provide health coverage to uninsured Americans must be evaluated for their costs and their potential for actually increasing coverage, especially for lower-income individuals, balanced with potential unintended consequences such as reducing incentives for employers to continue offering health coverage to employees and their families. Given the economic and other demographic diversity of Asian American and Pacific Islander populations, various proposals would have different impacts on Asian Americans and Pacific Islanders.

Recent data from California indicates that the reasons that Asian Americans are uninsured vary among specific Asian American populations. For example, Korean Americans in California have the highest percentage of Asian



Americans purchasing private insurance (21%) but also the highest percentage uninsured (40%) and the lowest percentage covered by job-based coverage (35%). (University of California, Los Angeles Center for Health Policy Research, April 1999). Southeast Asian Americans also have a low percentage covered by job-based coverage (37%) but the highest percentage of Asian Americans covered by Medicaid (34%).

While insurance pools for small employers have been effective in increasing the coverage available, recent research in California indicates that even existing programs are not well-known and are therefore under-utilized. (University of California, Berkeley, Center for Health and Public Policy Studies and University of California, Los Angeles Center for Health Policy Research January 2000).

Similarly, a recent review of various tax relief proposals found that many proposals would only result in a marginal increase in actual coverage, especially for lower-income individuals. For example, non-refundable tax credits would not necessarily result in increased coverage for lower-income individuals who do not owe significant taxes. In addition, matching the timing of tax relief with payments for health insurance coverage can increase the scope and efficiency of tax subsidies in increasing coverage. (Gruber and Levitt, January-February 2000).

Thank you again for the opportunity to testify before the Subcommittee and to respond to these questions. Please do not hesitate to contact me if you or any of the Subcommittee members have any additional questions.

Sincerely,  
Ignatius Bau, J.D.  
Policy Director

cc: Representative Sherrod Brown



**OKLAHOMA MEDICAL RESEARCH FOUNDATION**

825 Northeast 13th Street ■ Oklahoma City, OK 73104  
405/271-7766 ■ 1-800/522-0211 (in state) ■ Fax 405/271-4110

ARTHRITIS AND IMMUNOLOGY PROGRAM

Thursday, June 15, 2000

The Honorable Michael Bilirakis  
Chairman, Subcommittee on Health and Environment  
Committee on Commerce  
U.S. House of Representatives  
Room 2128, Rayburn House Office Building  
Washington, DC 20515-6115

Dear Representative Bilirakis:

I thank you for your interest in the initiatives that we are making in Oklahoma to address minority health research issues. In particular, my testimony focused upon our new Native American Biomedical Research Center here at the Oklahoma Medical Research Foundation. You had asked a set of questions to which we respond below:



Question #1: "Your testimony indicated that your research is based at the Native American Biomedical Research Center in Oklahoma. Is this a national center or is the research you do just regionally based?"

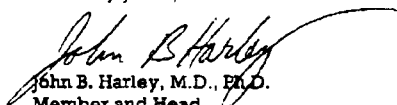
Answer: Our Native American Biomedical Research Center is nationally based. We plan to study health research issues of interest to our scientific staff here at the Oklahoma Medical Research Foundation that involve Native Americans wherever they may be located within the United States.

Question #2: "You mention that the prevalence of autoimmune disorders and diseases are significantly higher among Native Americans than in Americans of European descent. Do you know why this is the case?"

Answer: We do not know why some autoimmune disorders and diseases are much more prevalent in Native Americans or even why they vary so widely in their prevalence and expression among different Native American groups. Scleroderma, for example, has a prevalence that is more than 100 fold higher in the Oklahoma Choctaw than it is in Americans or European descent or in other Native American groups. (It is even much higher than in other Choctaw groups.) We hope that some of the research done in the Native American Biomedical Research Center at the Oklahoma Medical Research Foundation will focus on this and other problems. Indeed, this is one of the major reasons that this center is needed. We are, in fact, suspicious that the genetic differences among Native American groups as well as between Native Americans and European Americans may explain many of the differences we now observe.

Thank you very much for your interest in our testimony. We hope that we have made a constructive contribution toward making progress with these important issues.

Sincerely yours,

  
John B. Harley, M.D., Ph.D.  
Member and Head  
Arthritis and Immunology Program

cc: J. Donald Capra, M.D.  
President  
Oklahoma Medical Research Foundation

Morris Reichlin, M.D.  
Scientific Director  
Arthritis and Immunology Program

Andrea Miles  
Public and Media Relations  
Oklahoma Medical Research Foundation

JBH/adc



## DEPARTMENT OF HEALTH &amp; HUMAN SERVICES

Public Health Service

July 6, 2000

National Institutes of Health  
Bethesda, Maryland 20892

The Honorable Michael Bilirakis  
Chairman, Subcommittee on Health and Environment  
Committee on Commerce  
U.S. House of Representatives  
Washington, D.C. 20515

JUL 13 2000

Re: Follow-up Questions for Dr. John Ruffin, Associate Director, Research on  
Minority Health, National Institutes of Health

Dear Mr. Chairman:

This letter is in response to your request that I respond to questions related to my testimony before the Subcommittee on Health and Environment on May 11, 2000. Your questions and my responses are provided below.

QUESTION 1

I am curious in knowing more about the NIH's Minority Health Initiative. On your web site it says this program "supports biomedical and behavioral research aimed at improving the health of minority Americans and research training programs designed to increase the numbers of underrepresented minorities in all aspects of biomedical and behavioral research." In your opinion, how would the proposed National Center for Research on Minority Health function in relation to your Office of Research on Minority Health? Would its mission be the same? How would the proposed Center's role differ from that of the office you run at the NIH today?

RESPONSE

In my opinion, the establishment of the Center for Health Disparities and Minority Health Research would effectively incorporate and expand the original mission and authorities of the Office of Research on Minority Health. This means that a center for health disparities research at the NIH would be "inclusive" rather than "exclusive" with inclusiveness based on an empirically demonstrated disproportionate burden of morbidity and mortality. In particular, the Minority Health Initiative budget would be consolidated with the existing Health Disparity Budget to create a "Center budget" to be used operationally to focus, coordinate, and assist the NIH Institutes and Centers in their efforts in the area of health disparities. In my opinion, no attempt should be made to effectively uncouple minority health issues from health disparities. These issues are intrinsically linked and must remain coupled in order to generate maximal investment of focus and resources to alleviate health disparities.

Regarding the mission of the proposed Center, it is my perspective that a major focus of the Center would be to continue the Minority Health Initiative's focus on reducing and ultimately eliminating health disparities in minority populations. In addition, the proposed Center would continue the office's focus of designing, promoting, and supporting programs aimed at expanding the participation of underrepresented minorities in all aspects of biomedical research.

Regarding my opinion as to how the role of the proposed Center would differ from that of the office I now direct, I would reiterate that the Center would effectively broaden the original mission and authorities of the Office of Research on Minority Health. The proposed Center would be unnecessarily narrow in focus, in my opinion if its mission were not expanded to include health concerns of other populations that, while having been exempt from institutionalized racism and discrimination, have not been exempt from the impact of poverty on their health status - these populations are the "underserved." Accordingly, establishing programs within the Center to address the disproportionate burden of illness borne by the underserved would also be a priority. The proposed Center, in my opinion, would address other defined areas of disparities as deemed



appropriate to its expanded mission. The Center would also have expanded authorities in the areas of grant making, capacity building, and coordinating and reporting on Trans-NIH efforts on health disparity and minority health research. Also, in my opinion, the proposed Center could adopt a role that models, at least in some respects, the partnerships that the Fogarty International Center has with the various NIH Institutes and Centers. Fogarty has an outstanding relationship with the other NIH Institutes and Centers. And although Fogarty is recognized as the international arm of the NIH, the other NIH Institutes and Centers independently support international research initiatives. In fact, the international research support provided by the NIH Institutes and Centers far exceeds that provided by Fogarty.

#### QUESTION 2

How is your office funded today? Is it allocated funds from global NIH budget, or do your funds come from funds allocated to the individual institutes at NIH? Is there a separate stream of funds dedicated to your office?

#### RESPONSE

The Office of Research on Minority Health is currently funded annually through Office of the Director appropriation. The funding from the ORMH does not come from the NIH Institutes. The funding stream from the ORMH is identified in the Congressional Budget Justification for the OD appropriation as the specified line item entitled "Research on Minority Health."

#### QUESTION 3

As you are aware, H.R. 3250 proposes that the President and OMB allocate funds directly to the proposed Center for Minority Research at the NIH, without passing them through the Secretary of HHS or the NIH Director. Do you know of any other programs or Institutes at the NIH that get their funds this way? Does the NIH have an opinion about this type of directed funding?

#### RESPONSE

The allocation of funds, by the President and the OMB, directly to agencies within the NIH, is called "bypass funding." To my knowledge, the Office of AIDS Research in the NIH Office of the Director is currently funded in this manner. Section 2353(d)(2) of the Public Health Service (PHS) Act, 42 U.S.C. 300cc-40b(2), provides that the Director of the Office of AIDS Research, NIH, "shall receive directly from the President and the Director of the Office of Management and Budget all funds available for AIDS activities of the National Institutes of Health." The FY 2000 Appropriations Act implements that provision, and section 2353(d)(3) of the PHS Act, in Section 208 states: "of the amounts made available in this Act for the National Institutes of Health, the amount for research related to the human immunodeficiency virus, as jointly determined by the Director of the National Institutes of Health and the Director of the Office of AIDS Research, shall be made available to the "Office of AIDS Research" account. The Director of the Office of AIDS Research shall transfer from such account amounts necessary to carry out section 2353(d)(3) of the Public Health Service Act."

It is my understanding that, except for the Office of AIDS Research, the NIH does not advocate "bypass" funding.

Sincerely



John Ruffin, Ph.D.  
Associate Director for Research  
On Minority Health



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary  
Office of Public Health and Science

Assistant Secretary for Health  
Surgeon General  
Washington, D.C. 20201

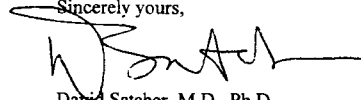
JUN 29 2000

The Honorable Michael Bilirakis  
Chairman, Subcommittee on Health and Environment  
Committee on Commerce  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Mr. Chairman:

Thank you for the opportunity to answer additional questions from your hearing on May 11, 2000 on H.R. 3250, the "Health Care Fairness Act of 1999." The requested answers are attached and I hope you will contact me if I or others in the Department can be of additional assistance.

Sincerely yours,



David Satcher, M.D., Ph.D.  
Assistant Secretary for Health  
and Surgeon General

Enclosures: -  
Answers to Subcommittee on Health and Environment  
June 12, 2000 letter from the Secretary to Chairman Bilirakis



**Question 1. What is the Administration's position on H.R. 3250?**

**See following letter from Health and Human Services Secretary Donna Shalala.**

THE SECRETARY OF HEALTH AND HUMAN SERVICES  
WASHINGTON, D.C. 20201

June 12, 2000

The Honorable Michael Bilirakis  
Chairman, Subcommittee on Health and Environment  
Committee on Commerce  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Mr. Chairman:

This letter is in response to your request for views of the Department of Health and Human Services (HHS) on H.R. 3250, the "Health Care Fairness Act of 1999".

In summary, this bill would do the following:

- establish a National Center for Research on Minority Health and Health Disparities at the National Institutes of Health (NIH), responsible for developing and implementing a balanced and comprehensive research agenda that addresses the unequal burden of morbidity and mortality in racial and ethnic minorities;
- authorize the Agency for Healthcare Research and Quality (AHRQ) to conduct and support research to improve minority health care service quality and outcomes;
- require the National Academy of Sciences to study HHS's system of data collection on race and ethnicity;
- create new grants for health education (graduate medical education and continuing medical education) curricula development on health disparities;
- authorize HHS to conduct a public awareness campaign to inform the public about programs and activities of the Office of Civil Rights in HHS.

Compelling evidence that race and ethnicity correlate with persistent, and often increasing, health disparities among U.S. populations demands national attention. Indeed, despite notable progress in the overall health of the Nation, there continue to be disparities between the burden of illness and death experienced by African Americans, Hispanics, American Indians and Alaska Natives, and Asian Americans and Pacific Islanders and that of the U.S. population as a whole. Current information about the biological characteristics of racial and ethnic groups does not explain the health disparities between these groups and the white, non-Hispanic populations in the United States. These disparities are believed to be the result of the complex interaction among genetic variations, discrimination, socioeconomic status, specific health behaviors, and environmental factors.

The proposed Health Care Fairness Act of 1999 (H.R. 3250) addresses several of the key elements the Department has identified as essential to a comprehensive approach towards eliminating disparities:



- developing a balanced and comprehensive research agenda that addresses the unequal burden of morbidity and mortality in racial and ethnic minorities;
- supporting efforts to improve the quality and outcomes of health care services and addressing the social determinants of health, including, but not limited to, access to health care;
- strengthening the data collection infrastructure of HHS;
- recognizing the important role of the Office for Civil Rights;
- supporting graduate health care education curriculum development, and continuing medical education efforts focused on the disparity in health and health outcomes, and to increase the knowledge base with respect to cultural competency.

We do have concerns about proposed section 485E(h), which would provide that the new Center's budget request would be transmitted without change to the President and to the Congress. Such bypass budget provisions result in transmittal of narrow budget requests developed without regard to competing priorities of the Administration. They can easily lead to an impression that the Administration is not fully committed to eliminating health disparities based in race or ethnicity. Such an impression would be absolutely false -- the Administration is committed to eliminating such disparities by the year 2010, and has affirmed this commitment in Healthy People 2000, the health-promotion, disease-prevention agenda for the Nation for the first decade of the twenty-first century.

We support the goal of training health professionals to reduce disparity in health outcomes, but believe that this is better achieved by integrating cultural competency training as a part of the existing Health Resources and Services Administration (HRSA) health professions grants. For example, HRSA finances training experiences that develop cultural competence through its Centers of Excellence grants and similar grant programs. The Administration remains committed to supporting cultural competency training to meet the unique needs of the underserved.

We suggest that section 502 also include the State Children's Health Insurance Program (SCHIP) in addition to the Medicare and Medicaid programs.

The elimination of disparities is an achievable goal that requires bringing all our forces to bear -- a balanced community health system, a comprehensive research agenda that addresses the unequal burden of morbidity and mortality in racial and ethnic minorities, training a multicultural workforce that is sensitive to the culture of its members, data collection that includes all the inhabitants of this country, and one set of quality health care delivery goals for all. I am encouraged by the broad and bipartisan consensus that is developing around HHS's efforts to eliminate disparities in health. The demographic changes that are anticipated over the next decade increase the importance of addressing disparities in health status. Groups currently experiencing poorer health status are expected to grow as a proportion of the total U.S. population; therefore, the future health of America as a whole will be influenced substantially by our success in improving the health status of our racial and ethnic minorities. H.R. 3250 will both support and enhance our current efforts and activities.

We therefore support enactment of H.R. 3250

The Justice Department has informed us that certain aspects of the bill raise constitutional issues. We understand that the Department of Justice will be submitting its views on these aspects of the bill and on possible ways of strengthening the legislation to address its concerns. We defer to the Department of Justice on those issues.



The Office of Management and Budget has advised that there is no objection to the presentation of this report from the standpoint of the Administration's program.

Sincerely,



Donna E. Shalala

**Question 2a.** Are you aware of GAO's findings that "evaluations have not shown that health professional education and training programs under the PHS Act had a significant effect on those changes that have occurred in the supply, distribution, and minority representation of health professionals?"

ANSWER: Yes, we are aware that in 1994 the GAO issued a report indicating that the supply of health professionals has increased faster than the population, but that data were unavailable to show whether increased supply translated into more access to care for rural and underserved areas. Similarly, the report indicated that although the number of minorities in health professions is increasing, data are inconclusive as to whether these increases improve access to care for underserved populations. Evaluations have not shown if and how the \$2 billion investment has resulted in changes in distribution and minority representation of health professionals. On April 27, 1997 in follow-up testimony before what is now the Subcommittee on Public Health, Senate Committee on Health, Education, Labor and Pensions, GAO commented that lacking common program goals, outcome measures, and reporting requirements it will be difficult to measure the effectiveness of Title VII and VIII programs which are authorized to support a broad range of health care objectives.

**Question 2b.** Has the Department done anything in this area to ensure that those health education programs that are available to minority health professionals today are meeting their goals?

ANSWER: The Health Resources and Services Administration, which administers the grant programs under Title VII and Title VIII of the PHS Act, has taken the following steps:

Identified improvement in the racial/ethnic diversity and the geographic distribution of the health professions as the two primary education related objectives needed to improve access to health care for the underserved,

Established a funding preference for programs that have demonstrated a record of training individuals from minority backgrounds, and an initiative that gives special consideration to programs that work with elementary, middle and high schools on activities designed to attract and assist minority students interested in a health professions' career,

Developed the Comprehensive Performance Management System (CPMS), a survey of grantees used to measure the progress that Title VII and VIII programs are making toward increasing the racial/ethnic diversity and improving the geographic distribution of the health professions. Data from the CPMS shows that Title VII and VIII programs graduate 2 to 5 times more minorities proportionately than the average for all health professions programs. In addition, HRSA program graduates are 3 to 10 times more likely than average to practice in underserved areas.

**Question 2c.** What is your understanding of how the education programs that are proposed in HR 3250 would complement other health professional education programs in the PHS Act. Are they similar programs or are they different?



ANSWER: As proposed, HR 3250 would allow HRSA to provide grants to institutions for the sole purpose of developing curriculum that would help reduce disparities in health care outcomes and to teach cultural competence in both graduate medical education and continuing medical education. This educational component of the Bill would complement such Title VII and VIII programs as Centers of Excellence and Departments of Family Medicine programs which allow (but do not require) curriculum development as part of its larger activities. HR 3250 would expand upon these curriculum provisions by providing funding for cultural competency curriculum development specifically. The health professional education programs of the Public Health Service Act are very different from the programs proposed in H.R. 3250. For example, Title II of H.R. 3250 requires the Director of AHRQ to conduct and support research to improve the quality and outcomes of health care for minority populations, to identify the causes of health disparities for minority populations, and to conduct and support research and demonstration projects aimed at eliminating health disparities for minority populations. It requires AHRQ to support health care research, health care research training, and the development of health care research capacity among minorities and minority institutions. Titles VII and VIII of the PHS Act support grants and loans to institutions and individuals in order to increase the supply, distribution, and minority representation of health professionals in order to improve health care access for underserved populations. Thus, H.R. 3250 complements health professional education programs of the Public Health Service Act by adding a focus on the conduct of research and demonstration projects to eliminate health disparities for minority populations.

**Question 3. Would you agree or disagree with the American Cancer Society's statement that, "research shows that condoms cannot protect against infection with HPV?" Would you say that there is a false sense of security that is placed in condoms for viral infections such as HPV? Should Americans be warned that condoms do not protect against HPV?**

ANSWER: Of the approximately 80 different types of human papillomavirus (HPV), approximately 50 are considered to be non-genital (e.g., causes warts on hands and feet) and are almost always transmitted in a non-sexual manner. Of the approximately 30 genital types, sexual intercourse appears to be the predominant route of transmission although non-sexual routes of transmission are possible. The most reliable means of preventing sexual transmission of genital HPV is, therefore, likely to be abstinence. Condoms should provide protection if they cover the infected genital skin and if they are used consistently and correctly. Theoretically, condoms are likely to be less effective in preventing infections, such as genital HPV that can involve external genital skin not covered by a condom, than they are for infections that are limited to specific mucosal areas and spread by semen (e.g., gonorrhea, human immunodeficiency virus [HIV]). The protection provided by condoms has been difficult to evaluate because current laboratory tests for HPV infection cannot determine whether an infection is new or was acquired months, or even years, earlier. Studies that attempted to assess male condom benefit for women have generally found no evidence of protection against infection; however, existing reports have not adequately assessed consistency and correctness of condom use, and in some of the studies, HPV infection may have preceded condom use. In contrast, some studies suggest a benefit of condoms for men.

In April 1999, the Centers for Disease Control and Prevention (CDC) and the American Cancer Society (ACS) hosted a meeting of expert consultants to address various aspects of HPV infection, including primary prevention, the role of HPV testing in cervical cancer screening, public and provider awareness, and surveillance for HPV. Participants' expertise included the biology and epidemiology of HPV, clinical management, laboratory sciences, behavioral sciences, health education, health services research, and sexually transmitted diseases (STD) and cancer prevention programs. This workgroup agreed that, while existing data were not supportive of a benefit of male condoms—especially for women—the existing studies had serious methodologic limitations and a randomized controlled trial would be the only study design that could clarify the issue. Such a trial, however, would be difficult to conduct and expensive, and a more efficient approach would be to include HPV outcomes in prevention trials being undertaken for prevention of HIV or other STD, in which use of condoms or microbicides could be carefully documented.



In addition, there is limited data on public awareness and perceptions regarding all aspects of HPV infection. Most experts believe that the American public has very limited knowledge that HPV is an STD and that it is linked to cervical cancer, and they expressed this belief during the 1999 consultation cosponsored by CDC and ACS. Participants in this consultation addressed whether public education efforts should be undertaken to raise public awareness about HPV.

In June 2000, the National Institutes of Health (NIH) and CDC established a workshop to examine the available scientific evidence on the effectiveness of the male condom to prevent STDs and to identify research needs and opportunities. This workshop also aimed to lay the scientific foundation for future considerations of public health messages about condom use and effectiveness. In its report, the workgroup stated that promotion of greater awareness that cervical cancer is linked to an STD could conceivably undermine general support for Papanicolaou (Pap smear) screening programs or could lead women or providers to decide that a woman considered to be at low risk for an STD does not need a Pap smear. Directing prevention messages to the general public is further complicated by the lack of clarity of what the most appropriate health care and prevention strategies are for HPV infection, given that most infected persons are asymptomatic, the overwhelming majority will not suffer any adverse consequences, data are lacking that document that condoms are effective for HPV prevention, diagnostic services are relatively expensive, and diagnosis of HPV infection has not yet been demonstrated to lead to improvement in health outcomes. The workgroup stated that it may be counterproductive to promote messages that increase anxiety in the absence of effective strategies to reduce risk for infection. Prevention messages must be carefully crafted to address these complexities, and assessment of such messages should be a critical element of research. The workgroup concluded that pilot public education programs should be carried out in selected areas to assess optimal form and content of public awareness messages.

**Question 4. One of the most severe minority health disparities among Native Americans is diabetes and the complications that result from this disease. The FY 2000 Interior Appropriations bill included report language expressing the concern of Congress about the high rate of amputations among Native Americans. Since Congress has directed IHS to develop a plan of action to strengthen its podiatry care program, the Committee requests an update on the development and implementation of this report. Additionally, Congress directed the agency to develop this podiatry care plan with consultation from NIH, CDC, and APMA. The Committee requests IHS to inform the committee on the level of communication that has taken place between the agency and NIH, CDC, and APMA regarding this plan.**

ANSWER: The Indian Health Service addresses podiatry care through clinical and public health approaches on several levels within the Indian health care system. The Indian Health Service's commitment to strengthening their podiatry program and reducing the high rate of amputations is being addressed through the following activities:

- The Balanced Budget Act of 1997 provided \$150 million over 5 years to Indian Health Service for the establishment of grants for special diabetes programs for Indians. As a result of these funds, 77.6% of the grant programs now focus on foot screening and education. Foot care assessment and treatment is based on the IHS Bemidji Area's Staged Diabetes Management guidelines (implementation of the guidelines in the assessment and treatment of diabetes related foot complications decreased lower extremity amputations by 48%; 1997) and on NIH research with the Pima Indians. The IHS Diabetes Care and Outcomes Audit, 1992 - 1998, reveals a steady increase in the percentage of comprehensive foot exams. This trend should continue with the continuation of the Balanced Budget Act grant programs.
- The IHS collaborates with researchers at NIH and CDC Diabetes Programs on new findings and disseminates these findings throughout the Indian Health Service diabetes network at regional and local levels. This collaboration is ongoing and IHS is an active member of each agency's health disparities workgroup.



- Indian Health Service continues to operate with limited resources and too few podiatrists and physical therapists to adequately meet the needs of Native Americans. The IHS podiatrists, in addition to their clinical functions, assist in training public health nurses, community health representatives and clinicians on appropriate screening and foot care to provide the opportunity for intervention at all levels of patient care.

**Question 5.** I am curious in knowing more about the NIH's Minority Health Initiative. On your web site, it says this program "supports biomedical and behavioral research aimed at improving the health of minority Americans and research training programs designed to increase the numbers of under represented minorities in all aspects of biomedical and behavioral research." In your opinion, how would the proposed National Center for Research on Minority Health function in relation to your Office of Research on Minority Health? Would their missions be the same? How would the proposed Center's role differ from that of the office you run at NIH today?

ANSWER: The mission of the proposed Center would be substantially broader, but not inconsistent with the current mission of the Office of Research on Minority Health (ORMH). HHS anticipates that ORMH would be part of any new Center focused on health disparities and minority health research. Thus, the new Center would carry on ORMH's mission of identifying gaps that impede sufficient progress regarding such research. Of course, the Center would have additional authority in the areas of grant making, capacity building, and coordinating Trans-NIH efforts on health disparity and minority health research.

**Question 6.** How is the Office of Research on Minority Health funded today? Are funds allocated from the NIH budget, or do the funds come from funds allocated to the individual Institutes at NIH? Is there a separate stream of funds dedicated to the Office?

ANSWER: The Office of Research on Minority Health (ORMH) is funded from monies appropriated annually to the NIH Director within the Office of the Director (OD) appropriation. The funding for ORMH does not come from funds allocated to the individual institutes at NIH. The funding stream for ORMH is identified in the Congressional Budget Justification for the OD Appropriation as a specific line item entitled "Research on Minority Health".

**Question 7.** As you are aware, HR. 3250 proposes that the President and OMB allocate funds directly to the proposed Center for Minority Research at NIH, without passing them through the Secretary of HHS or the NIH Director. Do you know of any other programs or institutes at NIH that get their funds this way? Does the NIH have an opinion about this type of directed funding?

ANSWER: There is no other situation which exactly matches the "direct funding" provision of H.R. 3250, although funding for AIDS research is somewhat analogous, as follows: section 2353(d)(2) of the Public Health Service (PHS) Act, 42 U.S.C. 300cc-40b(2), provides that the Director of the Office of AIDS Research, NIH, "shall receive directly from the President and the Director of the Office of Management and Budget all funds available for AIDS activities of the National Institutes of Health." The FY 2000 Appropriations Act implements that provision, and section 2353(d)(3) of the PHS Act, in Section 208 which provides: "of the amounts made available in this Act for the National Institutes of Health, the amount for research related to the human immunodeficiency virus, as jointly determined by the Director of the National Institutes of Health and the Director of the Office of AIDS Research, shall be made available to the "Office of AIDS Research" account. The Director of the Office of AIDS Research shall transfer from such account amounts necessary to carry out section 2353(d)(3) of the Public Health Service Act."

With the exception of funding for AIDS, NIH believes that directed funding is not appropriate. We believe it is entirely proper for NIH to compete for funding with the other discretionary programs of HHS and that, within NIH, all funding except that for AIDS should be on an equal footing so that the Director, NIH, can assure that the most scientifically meritorious proposals are funded through the highly respected peer review process.



**Question 8. Are a disproportionate number of minorities negatively impacted by the current employer-based health insurance?**

ANSWER: Data from the 1996 Medical Expenditure Panel Survey (MEPS) indicate that racial/ethnic minorities are far less likely than white Americans to be enrolled in employment-related health insurance. Among all nonelderly Americans (less than age 65), 71.4 percent of white Americans were enrolled in employment-related coverage, on average, during the first half of 1996 compared to only 47.9 percent of black Americans and 42.1 percent of Hispanic Americans. Among working Americans (ages 21 to 64), Hispanic male and female workers were less likely than black and white American workers to be offered employment-based coverage at their jobs. For example, only 56.2 percent of working Hispanic males and 62 percent of Hispanic females were offered health insurance by their employers during the first half of 1996. In contrast, 80.8 percent of white males and 75.4 percent of white females were offered coverage as were 74.6 percent of black males and 74.7 percent of black females.

**Question 9. How would increasing access to private health insurance through tax credits positively affect the current disparities in minority health?**

ANSWER: Minority groups are disproportionately represented among the uninsured. Current Population Survey data issued in October 1999 show that while 16.3 percent of the American people are uninsured, uninsurance rates for minority populations are higher: 21.1 percent for Asian Pacific Islanders, 22.2 percent for African Americans and 35.3 percent for Hispanics. This compares to an uninsurance rate of 11.9 percent for non-Hispanic whites.

Lack of health insurance contributes to minority health disparities. Data has consistently shown that the uninsured are less likely to have physician contact during the course of a year and more likely to lack a regular source of care. This is particularly true for the uninsured who are poor. The uninsured may often defer needed care, rely on hospital emergency rooms when acute problems arise, and lack opportunities for advice on healthy behaviors and other preventive measures from regular contact with health care practitioners. If the currently uninsured received health insurance coverage, it is likely that interactions with health care practitioners would become more routine and that over time, this would translate into improvements in health status.

Expanding access to health insurance through tax credits, however, poses problems, given the nature of the uninsured population. Uninsurance is highest among the Nation's poor, regardless of race or national origin. For those below the Federal Poverty Level, 32.3 percent of Asian Pacific Islanders and 28.8 percent of African Americans are uninsured. (These rates are statistically similar to the uninsurance rate for non-Hispanic whites of 28.5 percent.) An astounding 44 percent of poor Hispanics lack health insurance. For these poorest of Americans, many of whom will not have to file tax returns, a tax credit is an unwieldy mechanism for expanding insurance coverage. Even for those with somewhat higher but still low incomes, where large numbers of uninsured minority Americans are apt to cluster, the complications associated with a tax credit may discourage taking advantage of this type of option. We cannot predict take-up rates, but it is possible that this approach would do little to help the poor and near poor uninsured, and could, in fact leave them further distanced from the American mainstream.

**Question 10. Are there any non-financial barriers preventing more minorities from purchasing private health insurance?**

ANSWER: As noted in (#8), working Hispanic Americans are less likely than either white or black working Americans to obtain offers of employment-related health insurance from their jobs. Moreover, Hispanic males were the only racial/ethnic group for whom offers of employment-based health insurance declined over the last decade (the rate at which they were offered employment-based coverage declined from 64.1 percent of Hispanic male workers in 1987 to 56.2 percent of Hispanic male workers in 1996). Data from the 1996 MEPS also indicate that families with a Hispanic head of the family were more likely to report barriers to receiving health care (15.1



percent) than those with heads of family who were either black (9.9 percent) or white or other race/ethnicity (11.4 percent). The problems most frequently reported were the inability to afford care and insurance-related reasons. Among those families experiencing barriers, only 15.0 percent of Hispanic-headed families, 27.3 percent of black-headed families, and 20.6 percent of white and other headed families reported non-financial types of problems such as transportation, communication, or child care problems.

**Question 11. How significant are the misunderstandings in current minority patient/physician relations?**

ANSWER: Although racial and ethnic health disparities are rooted in economic and social problems that extend far beyond health care, the health care system still represents a critical source of inequities and potential focus for intervention. A growing body of evidence demonstrates that even when access to care, diagnosis and severity of illness are the same, members of different racial and ethnic groups use preventive, diagnostic and therapeutic services at different rates, suggesting that disparities emerge from the context of the doctor-patient interaction. Research supported by the Agency for Healthcare Research and Quality (AHRQ) and performed at the University of California-San Francisco, as well as other studies have demonstrated that ineffective communication, resulting in suboptimal decision-making, is a core problem that contributes substantially to the gap in health and health care between majority and minority populations. For example, studies have suggested that physicians make different treatment recommendations depending on race/ethnicity. Data from Cooper-Patrick L, et al., (JAMA 1999, Aug.11) "suggest that African American patients rate their visits with physicians as less participatory than whites. However, patients seeing physicians of their own race rate their physicians' decision-making styles as more participatory. Improving cross-cultural communication between primary care physicians and patients and providing patients with access to a diverse group of physicians may lead to more patient involvement in care, higher levels of patient satisfaction, and better health outcomes." AHRQ will soon be supporting a number of Centers of Excellence to improve our understanding and to eliminate minority health disparities. The study of the communication between patients and providers will be a major focus for the Centers.

**Question 12. Do behavioral choices more adversely affect minority health populations in comparison to majority health populations?**

ANSWER: According to 1997 data from CDC's Behavioral Risk Factor Surveillance System, disparities were found among five major racial and ethnic groups for access to health care; general health status and obesity; health risk behaviors such as physical activity, alcohol use, cigarette smoking, and safety belt use; and use of clinical preventive services such as cholesterol checks and screening for breast, cervical, and colorectal cancer.

Examples of the gaps in health risk behaviors and use of preventive screening among the races and ethnic groups include:

- Blacks, Hispanics, and Native Americans and Alaska Natives generally reported worse access to health care and poorer health status than whites or Asians.
- Except for Asians and Pacific Islanders, more than 30 percent of adults in all race ethnic groups reported not always wearing a safety belt when they drive or ride in a car.
- Regardless of race or ethnicity, two thirds of adults over the age of 50 had not been properly screened for colorectal cancer, a leading cause of death in the United States.

**Question 13. What are the top five lifestyle choices that most negatively affect an individual's health?**



ANSWER: In January 2000, the Department of Health and Human Services released Healthy People 2010. For the first time in the 20 year history of Healthy People, this document include 10 Leading Health Indicators. The 10 are: physical activity, overweight and obesity, tobacco use, substance abuse, responsible sexual behavior, mental health, injury and violence, environmental quality, immunization, and access to health care.

To live a healthy life, an individual is encouraged to:

- \* incorporate regular physical activity, preferably daily, into their lifestyle. This applies to children, adolescents, and adults of all ages. While the amount of physical activity may be dependent on the abilities of each individual, any amount of physical activity is better than none at all.
- make smart decisions regarding nutrition. All persons should choose a healthful assortment of foods that include vegetables, fruits, whole grains, fat-free or low-fat mild products, and fish, lean meat, poultry or beans, as recommended in the Dietary Guidelines for Americans. It is important to eat a sensible portion size whatever the food choice.
- not use tobacco products of any kind. The message here is very simple: do not smoke cigarettes, cigars, or use chew tobacco.
- avoid the abuse of alcohol and to not use illicit drugs of any kind. It is especially important that we keep all children and adolescents free of alcohol and illicit drugs. As an adult, if the choice is made to drink alcoholic beverages, it is important that it be done in only in moderation (2 drinks for men and 1 for women) and to never operate a vehicle while under the influence of alcohol.
- act responsibly about sexual activity. It is important that we promote the value of abstinence among the youth of this country. At the same time, for those youth who have made the decision to be sexually active, it is equally important that we promote condom use to prevent unintended pregnancies and sexually transmitted diseases including infection with the human immunodeficiency virus that causes AIDS.

According to the McGinnis and Foege (JAMA : 270:18, November 10, 1993: 2207-2212), the actual causes of death in the United State in 1990 were:

Actual Causes of Death in the United States in 1990

Estimated No. of Deaths	Percentage of Total Deaths	Causes
400,000	19	Tobacco
300,000	14	Diet/activity patterns
100,000	5	Alcohol
90,000	4	Microbial agents
60,000	3	Toxic agents
35,000	2	Firearms
30,000	1	Sexual Behavior
25,000	1	Motor vehicles
20,000	<1	Illicit use of drugs
1,060,000	50	TOTAL

Composite approximation drawn from studies that use different approaches to derive estimates, ranging from actual counts (e.g., firearms) to population attributable risk calculations (e.g., tobacco). Numbers over 100,000 rounded to the nearest 100,000; over 50,000 rounded to the nearest 10,000; below 50,000 rounded to the nearest 5000. From page 2208.



**Question 14. How can we encourage more individuals to take responsibility for their own health care?**

ANSWER: Individual responsibility for health begins with a combination of knowledge and understanding of the factors that influence one's health and the development of good health habits. Through research and outreach programs we have promoted the dissemination of a great deal of knowledge about topics such as transmission of HIV, the importance of diet and exercise, and the importance of screening for breast cancer, high blood cholesterol levels, and blood pressure. However, we must do more in two areas: we must develop better means of reaching the underserved segments of our population and better methods of engaging people in healthy lifestyles. This requires continued research on disease prevention strategies based on sound behavioral principles, targeting various arenas: communities, work sites, schools, families, and individuals.

**Question 15/16. Does reporting the full scope of HIV infection rather than just the end stage, AIDS, provide better opportunities to address prevention and care and any disparities that may exist? As you know, women and minorities are represented in higher proportions in HIV case reports than in AIDS case reports. Do you believe that changing Ryan White CARE Act funding formulas to take into account HIV cases, rather than just AIDS cases, would be an effective way to better target funding and address some of the health disparities that exist for minorities?**

ANSWER: CDC case reporting of new AIDS cases shows that most new cases are among minorities. For example, 65 percent of new AIDS cases in 1998 were African Americans and Hispanics. Twenty-three percent of new AIDS cases in 1998 were women. Thus, clearly, AIDS reporting is identifying the increases in AIDS incidence relative to minorities' presence in the overall population. Case reporting is also clearly revealing the increase in AIDS diagnoses in women. Since the nation is not yet fully reporting HIV incidence as well as AIDS, it is still difficult to know if the AIDS counts are a good proportional representative for the epidemic overall.

However, changing the funding formula to include HIV cases will certainly take into better account the prevalence of the total spectrum of the disease than counting only AIDS cases does at present. Even if including HIV case reporting tracks minorities and women in the same way as tracking AIDS does (e.g., the comparative proportional occurrence is roughly the same), and therefore not contributing much new to the understanding of the presence of minorities and women in the targeted populations, including HIV counts gives a much more accurate picture of the size of the epidemic burden on a particular community or State than does AIDS counts alone. Counting HIV cases may also greatly enhance our understanding of the prevalence of the epidemic in underserved areas in rural America, and could help to draw more needed resources to those States and localities.

Thus, on balance, in the future modifying the Ryan White CARE Act funding formulas to include the full spectrum of individuals with HIV disease may be the most accurate way to reflect the demand for HIV-related care and services. However, many States are just beginning the process of implementing surveillance for HIV infection, and it will be a number of years before these more comprehensive surveillance systems are reliable enough to guide formula driven funding.

**Question 17. Is partner notification a worthwhile prevention tool for HIV? Is it an effective intervention to identifying at-risk individuals and getting them into prevention and care programs?**

ANSWER: As HIV prevention activities have evolved, so has the terminology for informing the HIV-infected person's sex and needle-sharing partners of their possible exposure to the virus. Today, the term HIV partner counseling and referral services (PCRS) has replaced the term partner notification and more accurately reflects the range of services available to HIV-infected persons, their partners, and affected communities through this public health activity.



Through PCRS, persons--many of whom are unsuspecting of their risk--are informed of their exposure or possible exposure to HIV, and can choose whether to be tested. If found to be infected, they can seek medical treatment and practice behaviors that help prevent transmission of HIV to others and reduce the risk of becoming infected with other STDs. If they choose not to be tested, or if they are found to be uninfected, they can receive counseling about practicing safer behaviors to avoid future exposure to HIV. PCRS is most effective when it is a component within a more comprehensive plan for HIV prevention and treatment services.

PCRS can be instrumental in identifying sexual and drug-injecting networks, which are made up of individuals who share social relationships involving sex or drug use and are at high risk for transmission of HIV or other STDs. Maintenance of strict confidentiality protections are critical, as PCRS is inherently a voluntary activity. Stigma attached to sexual behavior and substance abuse can preclude effective PCRS unless the trust of the HIV infected person can be gained. Future prevention interventions can then be more effectively directed, and the HIV risks within the network(s) potentially reduced. Network research, combined with new methods of virus typing and identification of recently infected persons, will contribute to a greater understanding of HIV transmission.

**Question 18. Is there any evidence to substantiate claims that name-based HIV case reporting discourages individuals from seeking HIV testing or care?**

ANSWER: CDC studies conducted to date suggest that name-based HIV reporting has not served as a major deterrent to testing, although concerns about testing have been reported among some subpopulations. For example, CDC has worked with six health departments to evaluate HIV testing patterns in the twelve months before and the twelve months after the implementation of HIV reporting. In these areas, the number of HIV tests increased in four States, and declined in two. The declines were not statistically significant and followed a decreasing trend in testing that began before the implementation of HIV reporting. CDC does, however, recognize that for some people, reporting may serve as a deterrent. The Agency, therefore, strongly supports the continued availability of anonymous testing. As additional areas implement HIV reporting, CDC will conduct ongoing evaluations to monitor the impact of this policy change on testing behaviors.

**Question 19. Intravenous drug use is a factor for the spread of HIV. Would you say that it should be a priority of this Administration to develop programs for the treatment of heroin addicts by a new class of heroin-blocking drugs?**

ANSWER: The heroin abusing population has grown larger and younger throughout the 1990's, forcing us all to take a closer look at how we can better prevent and treat heroin abuse and addiction. Given that drug use is the major vector for the transmission of HIV in men, women, children and adolescents, it is imperative that we develop effective strategies to curtail the spread of infectious diseases. Drug abuse treatment has been shown to be highly effective in prevention the spread of HIV. Recognizing this, NIDA researchers are pursuing new pharmacological and behavioral avenues for treating addiction to heroin as well as other drugs of abuse. Reducing the morbidity, mortality and cost to society associated with addiction is a critical public health need in this country. One of the ways to address this goal is through the development new pharmacological and behavioral approaches. This strategy is a vital part of the Administration's overall demand reduction efforts, which in turn plays an important role in reducing the spread of HIV.

It is estimated that 75%-80% of the opioid addict population are not receiving effective treatment, in part because of limited access to programs and medications. At present, only methadone and LAAM are approved for pharmacotherapies for the treatment of heroin addiction. One new drug treatment, buprenorphine and the buprenorphine/naloxone combination, recently developed by the National Institute on Drug Abuse (NIDA) shows great promise for treating heroin addiction. Buprenorphine and buprenorphine/nx, pending FDA approval, are expected to reach new groups of opiate addicts - those who do not have access to methadone programs, those



who are reluctant to enter methadone treatment programs, and those who are unsuited to them (such as first year opiate users and low dose addicts), for example.

Pharmacologically, buprenorphine is related to morphine, but is a partial agonist, meaning it possesses the properties of both agonists and antagonists. Partial agonists exhibit ceiling effects when used, and therefore have a greater safety profile than full agonists, such as methadone and LAAM. This means that buprenorphine is less likely to cause respiratory depression, the major toxic effect of opiate drugs, which will translate into reduced chance of accidental or intentional overdose. In addition, the properties of buprenorphine and buprenorphine/nx make it undesirable for diversion to illicit use, especially when compared with other existing illegal and legal opiate products.

Thus, buprenorphine, as well as a wide-range of other pharmacological and behavioral treatment strategies in development, are not only an integral part of the Administration's efforts to combat heroin addiction, but also allows us to increase the Nation's treatment capacity and expand the range of treatments options that can be used by physicians. NIDA estimates, in fact, that approximately 20-25% of the approximately 630,000 heroin addicts in need of treatment may benefit from the availability of buprenorphine and buprenorphine/nx.

**Question 20.** As you recognized in your testimony, the Administration has proposed a number of initiatives to address racial disparities in health care programs in the federal government and with the private sector. How will these initiatives be coordinated with the proposals put forth in H.R. 3250?

ANSWER: H.R. 3250 complements many of the ongoing and proposed efforts by the Administration to address racial disparities in health care programs. For example, the National Institutes of Health (NIH) has drafted a five year research Trans-NIH research agenda to address the unequal burden of morbidity and mortality in racial and ethnic minorities. Once finalized, this research agenda can serve as a framework for activities conducted by the proposed National Center for Research on Minority Health and Health Disparities at NIH. The HHS Data Council's recently completed inventory of HHS's health and human service data systems and accompanying report on racial and ethnic data needs could provide substantial input into the deliberations of the proposed National Academy of Sciences' study of HHS's system of data collection on race and ethnicity. Under its current authorization, the Agency for Healthcare Research and Quality is currently supporting research to improve minority health care service quality and outcomes. For FY2001, AHRQ is proposing to support activities to address the issue of racial discrimination in health care access and quality, develop measures and tools to improve health care for minority Americans, and train a diverse health research workforce in order to overcome these issues in the future. The Health Resources and Services Administration (HRSA) currently supports cultural competency training as a part of existing health professions grants such as the Centers for Excellence. As mentioned in Secretary Shalala's recent letter to you regarding H.R. 3250, the bill could reduce program flexibility for AHRQ and HRSA by containing unnecessary authorities and requirements for new and existing activities.

**Question 21.** Your written testimony states that "Vietnamese women suffer from cervical cancer at nearly five times the rate of which women." Why is that? Is it a cultural factor linked to the willingness to get screened? What is the Administration doing to reach out to this community?

ANSWER: Cervical cancer is a particular concern for minority and underserved populations in the United States. The incidence and mortality rates for cervical cancer are two to three times higher in Hispanic and African American women than in White women, and cervical cancer is the leading cause of cancer death in certain Hispanic and Asian populations in the United States. According to a report of the President's Cancer Panel, entitled "Concerns of Special Populations in the National Cancer Program," Vietnamese women have the highest cervical cancer incidence



in the U.S. and Korean women have the second highest incidence. In Native American women, the disease is much more aggressive and is found in younger women as compared with women of other races. A similar pattern for breast cancer has been observed, but insufficient data exist to support development of a hypothesis. Many of the ethnic differences are attributed to differences in known cervical risk factors, including long intervals since last Pap smear and factors which increase the risk of infection with the human papillomavirus (HPV).

The National Cancer Institute (NCI) has developed a comprehensive research program in HPV-associated disease. This program includes extensive study of the biology of HPV infection, focusing on how HPV infects normal epithelial cells, as well as the role of the HPV E6 and E7 proteins in blocking normal cellular control mechanisms. In addition, epidemiological studies are seeking to identify nutritional, environmental, and reproductive factors, which may increase the risk that HPV infection will lead to cancer. The cause for higher incidence rates of cervical cancer in some racial/ethnic groups is currently being assessed through epidemiological and biological research. We are also studying the role of the immune system in fighting off HPV infection. Women with Human Immunodeficiency Virus (HIV) infection, for example, are at increased risk for developing cancer when infected with HPV.

As mentioned above, screening for precancerous changes with the Pap smear has become an accepted part of cancer prevention in the developed world. The NCI currently funds research to improve the accuracy of Pap smears, to develop new screening tests for precancerous and cancer cells in the cervix, and to improve imaging of precancerous changes in the cervix as well as invasive cancers. The NCI also is funding research to improve Pap smear screening among poor women, elderly women, rural women, and women among racial/ethnic minorities.

The NCI currently has a partnership with Health Care Financing Administration (HCFA) to develop, implement and promote a short-term joint promotion campaign to increase physician awareness of the risk of cervical cancer among Medicare aged women and to reverse the perception in the medical community that cervical cancer is not a serious health concern for women in this age group. The campaign is meant to serve as an impetus for physicians to promote regular pap/pelvic examinations among women 65 and older and will work in conjunction with other ongoing information campaigns about cervical cancer. These campaigns are targeted to women ages 18 and older with a special emphasis on minority and medically underserved women. In order to reach out to underserved communities, information was distributed through minority media outlets to African American, American Indian, Asian, and Hispanic communities. Specific publications have been translated into Spanish and are currently being adapted for the Vietnamese community through collaboration with a group in California.

**Question 22.** You may be aware that while African Americans make up 12 % of the U.S. population, they comprise nearly half of the nation's jail and prison inmates. Demographically, minorities and women have some of the highest rates of HIV infection. According to the CDC, TB infection rates are substantially higher among inmates because the conditions associated with TB (poverty, drug use, HIV infection) are more common in the incarcerated population than the general U.S. population.

**What role do you see the Department playing in conjunction with the Department of Justice to address the health care challenges facing America's correctional facilities?**

ANSWER: Inmates have disproportionately higher rates of infectious diseases, substance abuse, high-risk sexual activity, and other health problems than affect the health of the larger community. Unless addressed in the correctional setting, inmates carry these health problems back to the community at large upon their release. Because prisoners are part of the community and because correctional health and public health are increasingly intertwined, CDC has established a Corrections and Substance Abuse Unit to develop and coordinate disease intervention, prevention, treatment, and care strategies for incarcerated populations across CDC; and involving Federal, State, and national health care and criminal justice organizations; and



community-based correctional settings and health care providers. Activities focus on increasing disease surveillance and behavioral intervention; fostering partnerships between criminal justice, health care, and community agencies; developing integrated models of care; including incarcerated populations in grant proposals and research initiatives; and disseminating guidance on best practices.

To prioritize health care access, prevention education, and continuity of care for inmates in jails and prisons, CDC has established interagency agreements with the Department of Justice, the National Institute of Justice, the Federal Bureau of Prisons, the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration, and the National Institute of Mental Health, as well as partnerships with national nongovernmental agencies in public health and corrections (e.g., the Association of State and Territorial Health Officials, the National Association of State and Territorial AIDS Directors, the National Commission on Correctional Health Care, the American Correctional Association, the American Jail Association, and the American Corrections Health Services Association).

**Question 23.** I was very pleased with the Report on Mental Health that your office produced earlier this year. Are there similar health disparities between ethnic groups with respect to mental illness?

ANSWER: Mental disorders and mental health promotion issues are experienced by all people regardless of race/ethnicity. Although the data is somewhat limited, there appears to be a higher prevalence of particular mental disorder within specific populations. Most information presented compares and contrasts rates in relation to whites. However, this presentation which results in rank ordering such as "higher prevalence," "lower prevalence" does not depict the impact of mental illness on the individual, family, community or any racial/ethnic group. Certain subgroups appear to have disparate mental health issues such as Hispanic women and depression;

Native Americans and suicide and post traumatic stress disorder; African Americans and schizophrenia; and Asians adolescents and depression.

There are known disparities which will be important to target. Perhaps one of the most important disparate issues related to racial/ethnic groups is the fact that they are underserved and/or unserved by the mental health service system. Access, availability, and culturally competent care mark the areas of greatest disparity. A constellation of barriers deters ethnic and racial minority group members from seeking treatment, and if individual members of groups succeed in accessing services, their treatment may be inappropriate to meet their needs. Such barriers include: a lack of trust about mental health systems, stigma associated with seeking services, cost and lack of insurance, and clinician bias. To improve treatment to these groups, advances in ethnopsychopharmacology and minority-oriented services as well as greater cultural competence in service delivery are being promoted.

To develop a fuller understanding of the issues related to cultural diversity and mental health services, we are presently working on a companion Surgeon General's Report on this topic to be published later in the year.



June 29, 2000

Responses to questions from Commerce Committee Subcommittee on Health and Environment

Regarding: Testimony on HR3250 by Gilbert H. Friedell, M.D. on May 11, 2000

1. **When we discuss 'health disparities' we are really referring to a number of different things. There can be differences in those who seek treatment and those who do not, and there can be difference in the way people are treated once they seek treatment. There can be physiological differences among ethnic groups who receive the same care that show disparities. Furthermore, we know there can be wide geographic disparities in treatment which may disproportionately affect minority groups because of where they live.**

**When the IOM looked at health disparities, what specifically was it looking for?**

Congress asked IOM to assess the range of research programs at NIH directed toward understanding and reducing the burden of cancer among ethnic minority and medically underserved populations. As such, the study committee did not attempt to define "health disparities," or elucidate the causes of these disparities. Your question is important because it identifies some potential sources of disparities in disease. These include disparities in access to care or preventive health services, differences in the quality and intensity of health care, and geographic differences. All of these potential sources of inequities in health must be identified and more thoroughly studied to determine their role in producing disparities.

The study committee did note, however, that assessing the burden of cancer must begin with a comprehensive surveillance effort, and that differences in cancer incidence, mortality, and survival rates must all be considered in determining needs of different groups. In addition, the burden of cancer should be determined by assessing not only overall cancer rates, but also rates of specific cancers that may be more prevalent among certain population subgroups. Asian Americans, for example, generally experience lower rates of cancer incidence than most White Americans. A closer analysis, however, shows that rates of some forms of cancer (e.g., stomach cancer among Korean Americans) are more prevalent among some subgroups than others. Such analyses may point to risk factors (e.g., diet) that should be more thoroughly studied to determine why the burden of this cancer is greater.



2. **You stated in your testimony that participation by minorities in clinical trials has improved over the years to the point where their participation in cancer trials is proportionate to the burden of disease in minority populations. Can you explain how the disparity that did exist in this area was remedied? What steps did the National Cancer Institute take?**

In a recent paper by Drs. Otis Brawley and Harold Freeman in the Journal of the National Cancer Institute these authors made the statement that participation by minorities in clinical treatment trials has gotten to the point where their participation is proportionate to the burden of disease in minority populations. The numbers of participants might be proportionate, but it is not clear that persons of various levels of socioeconomic status are included.

The increased participation by minorities in these treatment trials is, I believe, a result of intensive effort by NCI clinical cooperative groups to increase recruitment of minority patients. Patients primarily enter clinical trials on the advice of their surgeons, radiotherapists or - - most often - - medical oncologists. Occasionally patients themselves seek out additional treatment possibilities by contacting the Cancer Information Service or other sources of information, but primarily their entry into trials is because one of their physicians has recommended it. NCI has stimulated more cancer physicians to encourage patients of all races and ethnicities to enter treatment clinical trials.

3. **You stated in your written testimony that "the absence of minorities in some of these [cancer treatment] trials ... raises questions about how applicable the results are to minority populations," yet two pages earlier you state "there are no known biological boundaries that justify the division into races." Are those statements contradictory?**

I believe in my written testimony we referred to the absence of minorities in some prevention, rather than treatment trials. It was in this regard that I raised the question about the applicability of prevention trials to minorities based on the absence of minority participation in the trials. The example often given is the prevention trial utilizing tamoxifen in women thought to be at high risk for breast cancer.

It is true that "there are no known biological boundaries that justify the division into races", and it is possible that the results obtained from studying white women might be



extrapolatable to, for example, black women, but until we check this out we will not know for sure. The parallel involving gender is the now discredited idea that the results of clinical trials in men could be simply extrapolated to the diagnosis and treatment of women.

The statements are not contradictory, but are often a source of confusion, even among health researchers. There is wide consensus among anthropologists, geneticists, and other scientists that far greater genetic heterogeneity exists within "racial" groups than between groups. Human diversity cannot be adequately summarized according to the broad, discrete categories assumed by a racial taxonomy. Furthermore, geneticists cannot distinguish "racial" groups on the basis of genetic information.

There are some differences, however, among ethnic groups in drug metabolism and disposition. Environmental factors (e.g., multiple disease states, diet, exposure to alcohol and tobacco smoke, and stress) may affect drug response, and cultural or psychosocial factors may also affect the efficacy of or compliance with drug therapy. There are also genetically determined variations in drug response and genetic factors that produce differences among ethnic groups in metabolism rates, clinical drug responses, and side effects. These include such factors as inherited metabolic defects or specific enzyme deficiencies. These differences, however, do not vary consistently among population groups - in other words, clinicians cannot consistently predict drug response on the basis of a patients' ethnicity.

For all of these reasons, it is important to study the efficacy of clinical treatment in diverse study populations, especially where research or clinical experience suggests that differences in response to treatment may occur.

4. **As you know, nearly all cervical cancer is a result of infection by the human papillomavirus. This week Congress passed a bill which would require the Centers for Disease Control and Prevention to develop educational materials for health care providers and the public regarding HPV. Our colleague, Congressman Ernie Fletcher, stated on the floor of the House on Tuesday that "we have in Kentucky the highest rates of cervical cancer in the Nation." Why is that? What are the public health institutions doing in Kentucky to lower that number?**

I did not see the statement reportedly made by Congressman Fletcher from Kentucky that



"we have in Kentucky the highest rates of cervical cancer in the nation". However, I believe he was speaking of invasive cervical cancer in white women. I would clarify that statement by making it referable to the eastern Kentucky population where the incidence is significantly higher than that reported by NCI's Surveillance, Epidemiology and End Results (SEER) system for the general population and for the population of white women covered by SEER. The incidence in eastern Kentucky is approximately the same as that of the African American population in Kentucky.

I believe the high incidence of cervical cancer in eastern Kentucky is probably largely the result of human papillomavirus transmission through sexual intercourse at a relatively early age inducing successive changes in the cervical epithelium which go through stages of dysplasia, carcinoma in situ and invasive cancer. Comparable circumstances I believe are responsible for the relatively high incidence of cervical cancer among some minority populations. It has been suggested that poverty rather than race or ethnicity is a common factor in the incidence of cervical cancer among different populations.

This high rate of cervical cancer in Kentucky could be lowered if cases of dysplasia or carcinoma in situ - - both precursors to invasive cancer - - could be detected and treated, thus preventing the development of invasive cervical cancer. Since the 1950's the Department of Public Health in Kentucky has made Papanicolaou smear screening available at low cost or no cost to Kentucky women. This effort has been increased in the past few years with support from the Centers for Disease Control and Prevention breast and cervical cancer program. However, even if such services are available and accessible, a significant segment of the women in eastern Kentucky, particularly older women, do not avail themselves of the services. We have developed some innovative programs in Kentucky to increase the number of women screened through local health departments, namely the Mountain Surveillance, Counseling, and Outreach (MtSC-Out) Program and the program of community health advisors known as Kentucky Homeplace.

**5. Do you think it is important for women to be aware of this virus and that condoms do not provide effective protection against HPV infection?**

I believe it is very important to have an effective public information program regarding the human papillomavirus. As far as I know condoms do provide effective protection against HPV infection, but of course they must be used on all occasions of sexual intercourse and they must be used properly.



6. **I know that you have spent a significant part of your career in Appalachian Kentucky, and you have done some research on health disparities among the Appalachian population. Could you tell us about some of your work in this area, and whether this population faces similar health disparities?**

After working with Appalachian populations, particularly those in central Appalachia (West Virginia, Southeast Ohio, Eastern Kentucky, East Tennessee and Southwest Virginia) I have learned that health conditions in this rural, poor, 98% white population are comparable in many ways to the health conditions, ie., the poor health status, of African Americans, Hispanics, Native Americans and Asian Americans. Although there are a few apparently biological differences between these groups, eg., the high rate of diabetes among Pima Indians and the apparently higher mortality of breast cancer in African Americans compared to the overall white populations, the similarities appear to be due largely to poverty and being medically underserved. Insofar as cancer is concerned, as Dr. Harold Freeman, Chairman of the President's Cancer Panel, has said repeatedly, it is poverty rather than race which is responsible for higher mortality in all racial and ethnic groups.

In his landmark report for the American Cancer Society in 1986 Dr. Freeman and his colleagues "concluded that controlling for socioeconomic status greatly reduces, and sometimes nearly eliminates, the apparent mortality and incidence disparities between ethnic groups. The report further concluded that ethnic differences are largely due to socioeconomic factors in contributing to these disparities."

In a 1991 editorial in the Journal of the National Cancer Institute he said that "there is no known genetic basis to explain the major differences in cancer incidence and outcome between races. Poverty, in contrast, is associated with low educational level, substandard living conditions, and inadequate social - support network, unemployment, poor nutrition, risk-promoting lifestyle and diminished access to health care. Diminished access is often manifested by low quality and inadequate continuity of health care as well as insufficient access to methods of disease detection, diagnosis, and treatment and to rehabilitation. Evidence indicates that poor Americans have an increased incidence of cancer and 5-year survival rates 10%-15% lower than those for other Americans. I believe the same factors also have a negative effect on the overall health of poor populations regardless of race or ethnicity.



In the NIH monograph "Sowing Seeds in The Mountain", a compendium of articles about Appalachian health, Dr. Gary Burkett notes that "with the exception of a few diseases that are associated with affluence, a relationship between a wide variety of indicators of poor health status and low income levels has been demonstrated among the people of Appalachia. Lower income groups may experience a combination of decreased access to health care, increased risk to occupational and environmental hazards, and a greater tendency toward lifestyle habits that correlate with a low sense of control over one's destiny".

In another article in "Sowing Seeds", Dr. Barry Portnoy of the National Cancer Institute points out that there are "special populations" in the United States that are a higher-than-average risk of death, disease and disability. These groups include African Americans, Hispanics, Native Americans, persons older than 65, blue-collar workers, and low-income groups, all of which are "population groups identified as being medically underserved and having elevated health risks".

"However, significant national concern also exists about the health of rural populations. US rural communities have lower income, higher poverty, and less education than their urban neighbors. They have higher rates of chronic illness and disability and report poor overall health status than urban residence. In addition, rural residents have less access to health care services and are less likely to have health insurance. Because of the large proportion of low-income families, blue-collar workers, and medically underserved people residing in rural areas, rural populations are viewed as a special population." He points out that "Appalachia has the burden of including large numbers of these special populations within its boundaries."

Because of the high rates of coronary heart disease, cancer, cardiovascular disease and diabetes, Kentucky ranks first among the 50 states in lung cancer incidence and mortality, fourth in mortality from all cancer, sixth in mortality from cardiovascular disease (West Virginia is fourth), and is tied for sixth in mortality from coronary heart disease with West Virginia, Ohio. (Tennessee is fourth.) In eastern Kentucky the death rate from heart disease 21% higher than elsewhere in America while diabetes mortality is 20% higher than the national norm.



It is obvious to those of us working in Appalachia that we very badly need research on whether this population and minority and other sociologically disadvantaged populations are more susceptible to certain diseases and/or less responsive to standard therapies. We need data about incidence and the outcome of therapy for chronic diseases. It is also important to determine the stage at which these diseases are diagnosed and if primary, secondary or tertiary preventive measures are effective. This research, should be carried out by NIH, and should precede, or proceed in parallel with, health services research by the Agency for Health Research and Quality.

**7. How could our own national surveillance system be improved to tell us more about minority and medically underserved populations?**

One of the critical needs in our national surveillance system is for more information about chronic diseases, including cancer, in some specific populations. For example, we need more information about different American Indian populations with regard to different diseases, including cancer, where rates appear to differ between some tribes. Another example of information needed concerning special populations would be the funding and development of a cancer registry for American Indians in Oklahoma. A similar example would be a cancer registry for Northern Plains Indians. Both of these registries have been discussed, but active efforts at their development would fill a significant gap in our health surveillance system.

In addition to data about the incidence, diagnosis, treatment and outcome of chronic diseases, we need data about socioeconomic status. This is particularly important in dealing with the rural poor population. It has been suggested that since the level of formal schooling completed is a reasonable surrogate for socioeconomic status, an item providing this information on hospital and physician records could be readily obtained and would actually be quite useful in patient care. Again, although the level of formal schooling completed is not an exact surrogate for literacy, it would provide us with some information in this regard and health care personnel could tailor messages for patients based on this information.



Responses to questions for the record to AAMC President Jordan Cohen, M.D., House Commerce Subcommittee on Health hearing on Health Care Fairness Act, May 11, 2000

1. *You stated in your testimony that you believe research on minority health should be incorporated into the mission of each NIH institute and center, building on the scientific and clinical expertise that resides in these programs. You testified that the AAMC has traditionally not supported the creation of a separate budget by-pass for specific areas of research, which this bill does for the proposed new Center for Minority Health Research.*
- a) *Why has the AAMC traditionally opposed this type of directed funding for research programs?*
- b) *Do you believe that there is some danger in having a program which has its own budget that is not linked to the rest of the NIH institutes and centers – that the kind of coordination you hope for in research can be jeopardized?*

As a matter of long-standing policy, the AAMC is predisposed against the creation of new institutes and free-standing centers at the NIH, particularly when such structures may cut across the responsibilities of the existing disease-based institutes. Any proposal to change the organizational structure of the NIH raises significant scientific and administrative issues that must be evaluated against the larger question of whether creating a separate organizational entity will impede and isolate or promote and coordinate ongoing research activities.

The AAMC believes that the compelling need for additional research and researchers to address the issues surrounding health disparities justifies the establishment of a mechanism within the NIH to develop a strategic research plan for the whole of NIH, and that the Center for Minority Health Research will facilitate rather than impede the coordination of research activities within the individual institutes and centers.

2. *Your testimony states that, "AAMC has long been concerned about the need to attract and retain more underrepresented minorities into careers in biomedical and behavioral research." What is the AAMC position on legislation to expand the number of H-1B visas, which would have the effect of increasing the number of underrepresented minorities in biomedical and behavioral research positions?*

The AAMC has not taken a position on the current proposals to increase the number of H-1B visas. This decision was taken, in part, because of our concern with the potential impact of such an increase on the number of international medical graduates entering this country for graduate medical education. As stated in the attached letter, the AAMC opposes the use of the H-1B visa classification for foreign physicians to participate in graduate medical education in the United States.

3. *As you are aware, H.R. 3250 proposes that the President and OMB allocate funds directly to the proposed Center for Minority Research at NIH, without passing them through the Secretary of HHS or the NIH Director. Do you know of any other programs or institutes at NIH that get their funds this way at NIH?*

It is our understanding that section 405(b)(2)(C) of the Public Health Service Act [42 U.S.C. 284(b)(2)(C)] states that the individual institutes at the NIH shall "receive from the President and the Office of Management and Research Budget directly all funds



appropriated by the Congress for obligation and expenditure by the institute.” The only exception to this of which we are aware is with regard to the NIH Office of AIDS Research. Section 2353(d)(2) of the PHSA [42 U.S.C. 300cc-40b] states “the Director of the Office shall receive directly from the President and the Director of the Office of Management and Budget all funds available for AIDS activities of the National Institutes of Health.”

4. *Your written testimony states that AAMC traditionally has opposed set-aside programs for research that are not reviewable by research management, yet you support the creation of budget by-pass here in H.R. 3250. Is that because you do not trust the Clinton-Gore Administration to give this research a fair peer review? Why shouldn't this research face the same scrutiny given other research?*

The Association's testimony states we traditionally have opposed proposals to create by-pass budgets. The statement does not reference set-asides or review by research management. The AAMC strongly supports the peer review system and believes that research in this area should be given the same scrutiny as other research.

