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LANGUAGE AND RACIAL DISPARITIES

MARA YOUDELMAN:* I will address language access issues as they relate to health disparities. First, I will briefly tell you about my organization because we do a lot more than language access. I will then walk you through some of the issues surrounding language access and then I will talk about some of the work we were doing on health reform to remedy language access issues.

The National Health Law Program (NHeLP) is a national nonprofit law firm. Our overriding mission is to work on behalf of low and limited income individuals to improve access to and quality of care. I do a lot of work on civil and human rights issues and that is where our health disparities work comes in. I have been working on language access issues ever since I got involved with NHeLP about nine and a half years ago.

For about seven years now we have been receiving funding from the California Endowment for our language access work. In large part, this supports a broad national coalition of stakeholders who work together in areas of consensus to improve language access. It has brought together the folks who used to be at many of the health care provider associations—the advocates, the health care accrediting organizations, interpreting associations, companies that provide interpreters and translated materials, and others—to work together to raise awareness at the federal level and improve policies related to language access.

* Mara Youdelman has worked with the National Health Law Program since August 2000 on issues including Medicaid, language access, racial and ethnic disparities and data collection. She is the Director of the National Language Access Advocacy Project funded by the California Endowment to increase awareness of language access issues at the federal level.

She coordinates a national coalition to develop a consensus driven agenda to improve policies and funding for individuals with limited English proficiencies. She authored numerous publications on language access issues. Ms. Youdelman also chairs the Certification Commission for Health Care Interpreters whose mission is to develop and administer a national, valid, vendor-neutral certification program for health care interpreters. Prior to working with the National Health Law Program, she completed a teaching fellowship at Georgetown University Law Federal Legislation Clinic. She earned her J.D. with the Boston University School of Law and her LL.M. in advocacy from Georgetown University Law Center.

In terms of the demographics, in the United States over fifty-five million people speak a language other than English at home. In the health care field, we say that if you speak English less than very well, you are considered limited English proficient (LEP) and you are likely going to need assistance communicating with health care providers. Those who are LEP might need a provider who is bilingual, or they might need an interpreter who can translate conversations between providers and patients. They also need help understanding written materials. There is a lot of material that needs to be translated for these folks. About nine percent of the population is LEP for health care purposes.

In the health care provider setting this means that about eighty percent hospitals see LEP patients at least monthly. These statistics are derived from national surveys that NHeLP funded along with partners in the national coalition. This problem does not just affect the big states where lots of immigrants are. It is no longer just Illinois, California, New York, and New Jersey where the traditional pockets of immigrants have been. The same statistic holds true for small practices of general internal medicine physicians. We conducted a study with community health centers and the results indicated that eight-four percent of these clinics are providing daily care to patients with limited English proficiency. This is a widespread national issue that is really overlooked in a lot of ways.

There is a lot of documented research on the problems that people face when they have a limited English proficiency. One such problem was very well documented in a lawsuit out of Florida, which resulted in a \$71 million settlement for a young man who was left quadriplegic after being misinterpreted in the health care setting. There are lots of other horrible stories. For example, a six-week-old infant was admitted for a barbiturate overdose, which was caused by a dosing error when a LEP mother did not understand the medication instructions that were given by the doctor. The instructions were only available in English and they were not translated. Lots of issues, lots of stories, lots of horrible consequences.

Right now, NHeLP is doing research on malpractice and language access, which has always been of interest to us. We are frequently asked: Are there more lawsuits? Can we see more evidence about the consequences of poor language access? We have been

working with a malpractice insurer in California to review through their closed claims. Soon we will releasing an issue brief that documents a lot of malpractice cases where language barriers were at least one piece of the puzzle. In addition to sharing stories about the horrible effects of language barriers on health, NHeLP is really trying to build a legal case to make a change.

On the legal side, we have a strong case for requiring language services. Since 1964 Title VI of the U.S. Code has said that anyone who receives federal funds cannot discriminate on the basis of race, color or national origin. The Supreme Court and federal agencies like the Department of Health and Human Services (HHS) have said language can be a proxy for national origin. Therefore, if you receive federal dollars, you cannot discriminate based on language, meaning you should be providing meaningful language access to all patients in federally funded locations. Virtually every single health care provider is receiving some federal funding. They participate in Medicaid, the Children's Health Insurance Program (CHIP) or Medicare. They accept research funds from the Centers for Disease Control and Prevention (CDC) or the National Institutes of Health (NIH). Federal dollars touch virtually all aspects of health care. There really is, then, an expectation that health care providers provide language access. They should be providing interpreters and they should be translating materials. Still, the vast majority of providers are not doing that and as a result we still have significant health disparities.

In addition to federal law, there are many state laws affecting this issue. NHeLP conducted a national survey a couple of years ago looking at all fifty states and identifying statutes and regulations that address language access in health care. Every single state has at least two laws on point. Some states have extremely comprehensive laws and some have just minor provisions here and there. We also saw some recent trends. There is starting to be more attention at the state level to issues of language access. We have seen new educational requirements on cultural competency and language access for health profession students and continuing education for health care providers.

We have also observed that some states are developing standards for health care interpreters. Many providers do not understand that utilizing a family member to interpret between patient and provider is not the best way to go. Family members, children of patients in particular, often say that they are bilingual, but when they begin interpreting they face difficulties. Even if this individual is bilingual, he might not know how to translate medical terminology, or confidentiality explanations. On a related note, some states are starting to look at the issues of confidentiality certification standards for interpreters. Although private insurers who do not receive federal funds are not subject to federal non-discrimination laws, some states, such as California, are requiring private insurers to ensure that all network providers provide language access.

We have talked about some statistics, but who is considered LEP? Basically, anyone who cannot speak, read, write or understand English at a level that

permits effective interaction with health and social service agencies is LEP. A physician friend once reminded me that in the health care field you are not just dealing with English and Spanish, for example, but you are adding on two more languages: medical English and medical Spanish. That is why many people need assistance in interacting in English in the health care setting even if they effectively interact in English in other settings.

What has NHeLP been doing? We work extensively to improve language access through health reform. Although health reform is stalled, we still are optimistic. There were three main acts that members of our national coalition developed. We are trying to influence and address disparities through federal legislation. The first idea was to give states more money to provide interpreters through Medicaid and CHIP, the two public health programs that primarily are for low income individuals and children. Many states do not provide interpreters because it costs about fifty cents for every dollar earned. We wanted to increase federal payments to states to incentivize language access programs in public health care.

The second piece was to address language access through Medicare. Medicare serves the elderly and people with disabilities and does not pay for language services. We realized that Medicare could not support the estimated \$2.5 billion cost of providing language services. Instead we wanted to get the ball rolling by doing a one-year study to examine how Medicare could pay for language services and a three-year demonstration program to gather data and fund in-practice trials. The third piece was to work with health care exchanges—where people who do not get insurance through a public health program or their employers can buy private health insurance. We wanted to put requirements on plans participating in the exchange to provide culturally and linguistically appropriate services.

In the Senate, we were not able to get funding on these three ideas through Medicare or Medicaid. In the House of Representatives we were much more effective. The House allocated some of the increased Medicaid funds to hospitals to be used to pay for translation and interpreters. The House also had a number of provisions that would have required culturally and linguistically appropriate services by plans in the exchanges. The House was also going to require health care plans to use plain language in their communications, which really improves literacy for LEP patients. It is much easier to translate and understand plain English communications.

We are really trying to get the federal government, particularly the Centers for Medicare and Medicaid Services, which oversee the programs, to step up. We would like Medicare, for example, to translate forms so that providers across the country do not have to do it themselves. We would like to see these programs create a clearing house for materials to assist providers and insert requirements for language access in related regulations. Our next step is to await developments in health reform. In the meantime, we are looking at other legislation and administrative opportunities to advance language access in health care. We will continue to research and document needs and disparities to improve the likelihood that policy makers respond to this issue.

JULIA PIERCE:* At the Indian Health Service (IHS) we also face language barrier problems, but we are dealing with 564 different languages. IHS provides health services to the 564 federally recognized tribes in America. IHS serves 1.9 million of the nation's estimated 3.3 million Indian people. Many of those people live in Alaska in tiny villages that are ordinarily remote and isolated. IHS strives for maximum tribal involvement in the health services we provide, but there are budget limitations that make that challenging. Federal tribal relations are considered a political relationship, not a racial relationship, which allows a lot of the work IHS does and a lot of hiring to escape the Title VI Affirmative Action Laws. IHS actually has a preferential hiring policy that is established by statute. Many years ago, Congress found that Indian people related better to other Indian people who they felt had a better understanding of where they were from and the challenges they were facing.

IHS finds a basic problem between the federal and state relationship. Often the states think of tribes as separate states within states. States often believe that tribal people are not eligible for state-sponsored programs, but in reality the federal government is funding these programs and, of course, Indian people are citizens of their states as well as of their individual tribes. Indian people are eligible for state-sponsored programs just as anybody else is. It is a challenge we have to overcome.

Indian people have long experienced lower health status than other racial populations in America. On average, the life expectancy of Indian people is about four and a half years shorter than other races in the United States. American Indians and Alaskan natives die at a higher rate than other Americans from tuberculosis—about 750 percent higher; alcoholism—550 percent higher; diabetes—190 percent higher; unintentional injuries—150 percent higher; and homicide—100 percent higher. There are reasons for these disparities, many of which we have been examining for years.

When you really start looking at why there are such health care disparities, you have to look to history. Many Indian people are located in remote locations where there is no economic opportunity. Up until recently, these people did not have the same educational opportunities. Even Indian people who obtain their education away from their tribes have to deal with the

* Julia Pierce represents the Department of Health and Human Services, Office of General Counsel, Public Health Division, Indian Health Service Branch. She served as a licensed radiologic technologist at the Navy Hospital in the Navy Reserves from 1988 to 1996. Ms. Pierce worked as a radiologic technologist at the Medical College of Virginia in a community hospital while attending college and law school.

While attending the University Of Virginia School Of Law, she served as the president of the Native American Student Union. After graduating in 1998, she joined the Indian Health Service Branch of the Office of General Counsel where she served as team leader negotiating consistency among teens that negotiated the Indian Self Determination and Education Assistance Act contracts with Indian tribes. She was instrumental in transferring over \$2 billion a year from the federal government to tribes annually.

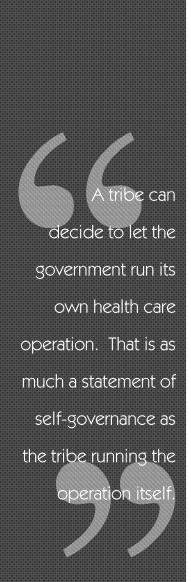
She has been involved with litigation at every level of the federal court system including the Supreme Court. She has also served on the team that developed the regulations required by Title V of the Indian Self-Determination and Education Assistant Act traveling throughout the country for over a year to meet various tribes for a consultation. Last year she completed the Department of Health and Human Services eighteen-month Senior Executive Service Candidate Development Program and was certified as an SES member in 2009.

ramifications of not being able to find a job in their field when they return to their reservations. All of this leads to health care disparities because health care is not just about the services available. IHS takes a holistic approach in native communities. Am I able to have the emotional well-being and intellectual stimulation to allow me to feel worthwhile? If I come back to my community, am I able to sustain myself? If I do not come back to my community, do I lose part of my culture? These are things that IHS considers in its provision of services. We also support native medicines. We are a federal agency that supports alternative medicine. In some of our contracts with native peoples we are intentionally vague about the medicine and techniques provided to tribal members. In these cases it would be sacrosanct to the Indian people to reveal their medicinal traditions.

While many Indian people are in rural communities, they are not the same rural communities that some of us grew up in. They are rural in the most extreme sense where many people do not have sanitation and running water. We are looking at disproportionate poverty and often discrimination in the delivery of the health care that is available. In these places, Indians are not revered as they often are on television or the movies. There is a lot of racial discrimination, a lot of cultural misunderstandings and a lot of ridicule for people who prefer to stay true to their cultural and traditional practices. These are the sorts of things that lead to disparities in health care that are not really openly discussed unless you set up a forum and that is what IHS, and in larger part, HHS, tries to do.



We have a policy of consultation with tribes on basically everything that we can afford to consult on. We are not an entitlement program hence there is not a never-ending well of funding under the department. We are able to provide the services that tribal people in the country deserve. We have a \$4 billion budget to serve about 1.9 million people in very remote locations. We are working to build hospitals and clinics because about fifty-seven percent of the Indian population is being served by basically forty-five hospitals and 600 clinics. We are providing health services either directly in places where tribes are not able to provide them for themselves or in places where tribes have gotten a bit savvier and have expertise, through the Indian Self Determination Act Contracts. This means that a tribe takes the funding the government would have spent and they provide the services for themselves. For us, that is a win. That is when we can actually see the



good work that IHS is doing and continue a government-to-government relationship.

If you have had an Indian law course, you are familiar with the *Worcester v. Georgia*¹ case, which established native tribes as dependent domestic nations. That is an interesting title. It sets up a guardian-ward relationship, which in its own way is a bit paternalistic. But, if you look at it in terms of a situation where the government is attempting to pay back a debt that is owed, it is not as paternalistic. We are sincerely trying to bring tribes to a level where self-determination is for everybody. A tribe can decide to let the government run its own health care operation. That is as much a statement of self-governance as the tribe running the operation itself.

As I said, we are under-funded. Four billion dollars seems like a lot but it is not when you are in health care. What we have done to try to make up for some of this disparity is to look into partnerships with not only other agencies within our department, but other departments at large. The Department of Housing has an Indian housing program. They are also responsible for sanitation in houses. The Department of Justice has real justice programs, which provide many of things that one would not necessarily think of as health care-related, like who provides guards for the hospital. IHS does not have the funding to address these health-related issues. We try to work with the Bureau of Indian Affairs. They provide Indian people with social programs.

We have set up partnerships not only throughout the government, but with private entities. Many of you may not know that Nike has designed a shoe for Indian people. Admittedly, it looks like a huge, hideous block, but many Indian people who have diabetes are also large. The size of these individuals is due to poverty and the food that the government gave Indian people on reservations. Nike has, in conjunction with IHS, provided a shoe that accommodates the wider, larger foot of Indian people. The purpose of entering into such a partnership is not only to get specifically designed shoe wear, but also to encourage exercise and to encourage care among private organizations about health on reservations. It has a secondary effect. Besides being able to supplement our budget it shows Indian people that there are people who care about them. The rest of the world has not forgotten that Indian people exist. We are trying to enter as many partnerships as possible. We have been encouraged to do this by the highest levels of government. President Obama has recently reissued the Executive Order on consultation, saying that if there is anything the federal

government is going to do that affects Indian people, they need to consult with Indian people.

IHS is a very interesting place to work because we not only deal with a section of society that most people know very little about, but we deal with a section of society that most people, if they really read history, would agree have not been treated particularly fairly. Amends need to be made.

LEONARD RUBENSTEIN:* We need to distinguish at least three kinds of disparities. One health disparity is disparities in access. The health care access debate in this country has been in the forefront for the last year. We know that not only do we have tens of millions of uninsured people, but that African Americans and other minorities are disproportionately uninsured. The second disparity is disparities in health status. We have supposedly had a national effort to eliminate health disparities by 2010. The third disparity is quality. I will discuss data about the last two types of disparities.

Just recently, the American Journal of Public Health published a report on how we are doing at addressing health disparities. For example, African-Americans have died from all causes at a younger age thirty-five percent more than Whites. The only outcome where Whites fair worse than African-Americans is deaths by suicide. Regarding tuberculosis, there is a 600 to 700 percent difference in deaths between African-Americans and Whites. Despite the supposedly enormous national effort to eliminate health disparities, at least half of the indicators have gotten worse since 1990 when measured by mortality indicators. We still have a stunning problem in disparities in health status. It is a very sobering set of data considering the decades of discussion and commitment, or supposed commitment, to reducing health disparities based on

People talk about quality of care even less frequently, because we assume that everybody gets the same quality of care. There are now numerous studies in peer-reviewed journals showing that African Americans and other ethnic minorities get worse quality of care than Whites. There are fewer referrals for renal transplants,

* Leonard Rubenstein is a renowned advocate for human rights and medical ethics. He is currently a visiting scholar at the John Hopkins Bloomberg School of Public Health, Center for Public Health and Human Rights and Center for a Livable Future. He is the former executive director of Physicians for Human Rights and was recently a senior fellow at the United States Institute of Peace. He coauthored a report on the disparities and quality of care and application of international human rights law and brought the issues to the U.N. Racism Conference in 2001.

less adequate pain medication for cancer, poorer HIV care, and fewer admissions to cardiac care units. You might think that this inequality is attributable to access to health insurance. But, if you look at the Medicare population where everyone has the same access, across indicators, across type of care, African Americans got worse care.

For a long time there have been efforts to address this problem through the Office of Minority Health. These efforts have not been very successful. It has been many years since a concerted effort was made to provide disparities data to the communities. For almost 10 years, legislation has not made it through Congress to require that. In the health care reform bills, there are provisions to assure that we collect data so that people can observe disparities on a national level and the community level. People would know what is going on in their communities and can organize around that. As of yet, we do not yet have that disaggregated data.



The second problem is how we think about disparities. In our legal system, we have had wonderful civil rights laws that are all written in basically the same way. They say if you are discriminated against, you may have a claim. If you have your rights violated, you can sue. However, international human rights law takes a very different approach to the concept. Discrimination does not create an automatic right to sue. Rather, the state has a responsibility to eliminate discrimination. In our system, civil rights are individual claim-based and create no responsibility to eliminate discrimination.

The United States is infamous for not adhering to or ratifying Human Rights Treaties. We have not ratified the Women's Convention. We have not ratified the Convention on the Rights of the Child. We have not ratified the Mine Ban Treaty. We have not ratified the Cluster Munitions Treaty. But, we have ratified the International Convention on the Elimination of All Forms of Racial Discrimination. This is not like all human rights treaties in the U.S. in that is not self-executed—you cannot sue based on this. In human rights, we are often without remedies. In fact, one

of my colleagues says the reason the human rights movement exists is because of the failure of law.

Human rights law may not provide a remedy in court, but there is a lot we can do with it. We can go to Congress with it. We can go to the public with it. We can go to our communities with it. It is incumbent upon us to learn about human rights law and how it applies, because as we have seen from the statistics, just talking about disparities is not sufficient. We have to think seriously about new ways to eliminate disparities.

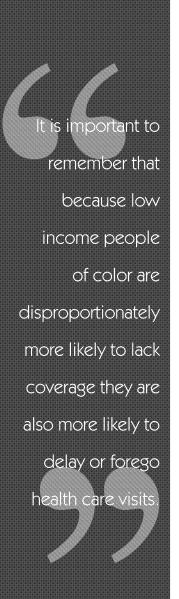
GINA E. WOOD:* I would like to highlight some of the work of the Joint Center for Political and Economic Studies on the status of health and equity affecting African Americans and other people of color, as well as possibilities for eliminating these inequities through the health reform bill. The Joint Center released a study entitled *The Economic Burden of Health Inequalities in the United States*.² We released it during a health reform briefing at the National Press Club which featured HHS Secretary Kathleen Sebelius. The study used data from existing federal health surveys and found that between 2003 and 2006, health inequalities in the U.S. for people of color costs more than \$50 billion a year. The direct medical cost over the four year period of the study amounts to a total of \$229.4

* Gina E. Wood is Deputy Director of the Health Policy Institute at Joint Center for Political and Economic Studies. She is the team leader supporting the implementation strategy for health policy institute programs, public and private sector partnerships, communication, research and policy analysis and resource development. Miss Wood has an exemplary public service background spanning 20 years in the state and federal level positions.

In light of her prior experience in a legislative and executive branches of Oregon State Government, the then Governor Jim Hodges of South Carolina asked her to join his cabinet as Director of the Department of Juvenile Justice. Subsequently she was confirmed as Director by the South Carolina State Senate. At the federal level, she served as Staff Director of the Coordinating Council on Juvenile Justice and Delinquency Prevention chaired by then Attorney General Janet Reno and comprised of leaders of key federal agencies. During her ten years, she led major interagency initiatives which garnered the support of the United States Congress and a number of foundations.

Ms. Wood is currently affiliated with the Women of Color Policy Network at the Robert F. Wagner School of Public Service in New York University and serves on the Board of Directors at Crittenton Services of Greater Washington. She is also the member of the Advocacy Committee of the Juvenile Justice for the Commonwealth of Virginia. In addition, she serves as the trustee on two national boards, the Coalition of Juvenile Justice where she chairs the Ethics and Cultural Diversity Committee and the National Crittenton Foundation. Miss Wood holds a bachelor's degree in communications from the University of Missouri.

Despite the supposedly enormous national effort to eliminate health disparities, at least half of the indicators have gotten worse since 1990 when measured by mortality indicators.



billion. The price tag of \$230 billion between 2003 and 2006 reflects only the *excess* cost associated with health inequalities. If we were to eradicate health inequalities, these excess costs would disappear.

For African-Americans alone, the direct medical expenditures due to health inequalities over the four year period was \$135.9 billion. A great deal of these direct medical expenditures due to health inequalities over the four year period were for hospital costs. It is important to remember that because low income people of color are disproportionately more likely to lack coverage they are also more likely to delay or forego health care visits. By the time such vulnerable patients end up in a hospital setting, their respective health conditions have worsened to the point of requiring far more rigorous medical interventions and treatment regimens. This may help explain some of the soaring health based medical care costs for African Americans and people of color. To reverse this trend, we need comprehensive health care reform that is actually designed to eliminate health inequalities. At the Joint Center we focus more on health inequities versus disparities. In short, eliminating health inequalities for African Americans, and certainly other people of color, is not only the just and moral thing to do, it is also the most cost-effective thing to do to restore the nation's physical health.

Let me say a few words about the indirect costs that result from health inequalities. Indirect costs include the loss of productivity, wages, absenteeism, use of family leave for avoidable illnesses and lowered quality of life due to illness, as well as premature deaths, which cause loss of wages, tax revenues, benefits and services for families of the deceased, and lower quality of life for family survivors. Researchers have calculated that the indirect costs of health inequalities added up to more than a trillion dollars from 2003 to 2006. When you add the direct and indirect costs of health inequalities together, the grand total is more than \$1.24 trillion in a four year period—more than the annual gross domestic product of India, the world's twelfth largest economy. You might ask who is paying this \$1.24 trillion bill. The answer is simple: all of us, through federal, state and local taxes, as well as increased costs for doctor visits, prescription drugs and medical procedures. Yet, eliminating racial health inequalities will do more than put the nation's fiscal house in order. It will also improve health status outcomes for people of color from cradle to grave.

We especially need to improve health status and outcomes for African Americans. Seventeen years ago the Joint Center published what was at the time a

pioneering document entitled A Health Assessment of Black Americans, which included noteworthy findings on African-American men and women's health. Although it is hard to believe, it was not until 1985 that HHS published an official report on African-American and minority health. The Office of Minority Health at HHS was established the following year, in 1986. Moreover the National Institutes of Health (NIH) did not adopt a policy that urged the inclusion of people of color and women in its clinical health research trials until two years later, in 1987. Three years later, in 1990, the NIH established the first Office of Research on Women's Health. We are still trying to understand the importance of women and communities of color to health outcomes.

Congress did not mandate the inclusion of people of color and women in all NIH supported clinical research until 1993. NIH is still attempting to overcome barriers to include more people of color and women in clinical research trials. One of the most pressing of such barriers is the continued lack of racial and ethnic diversity among health researchers and practitioners. We have an initiative that we have been working on with former HHS Secretary Dr. Louis Sullivan, who has made it his lifetime commitment to ensure that we have diversity within the health care profession.

I would also like to bring attention to heart disease in the U.S. and the implications for cardiac-related data on health disparities. According to a study reported in the September 16, 2009 issue of the Journal of American Medical Association, African-American patients who suffer cardiac arrest in a hospital setting are much less likely to survive than White patients. Although survival after having a cardiac arrest in a hospital setting is historically low, survival rates for blacks were significantly lower at twenty-five percent versus thirty-seven percent for Whites. This amounts to about a twelve percent absolute difference in survival rates. According to lead researcher, Dr. Paul S. Chan, a cardiologist at St. Luke's Mid-America Heart Institute in Kansas City, this twelve percent absolute difference in survival is the largest survival disparity for any medical condition. Much of this disparity is believed to result from the quality of hospital in which black patients receive care. Also, thirty-two percent of African-Americans have high blood pressure or hypertension, a leading risk factor for heart disease, compared to 22.5 percent of Whites in 2007. African-American men are thirty percent more likely to die from heart disease than their White non-Hispanic males according to 2005 data from the Office of Minority Affairs website.

The disturbing disparity between heart-related death rates for African-American males and White males of this country is not only stubbornly persistent, it also applies to females. Since 1997, the Joint Center has published the Women of Color Health Data Book. Our third edition of the Women's Health Data Book was released in 2007. As highlighted in this latest data book, African-American women are more likely to be obese and more likely to have sedentary lifestyles. Fifty-five percent of African-American women reported they had sedentary lifestyles between 1999 and 2001, which means they did not engage in light physical activity for ten minutes at a time in this period. They are more likely they have elevated levels of lead in blood, which is associated again with high blood pressure. They are more likely to die of heart disease, more likely to die of diabetes related causes and more likely to have a shorter life expectancy. Equally alarming are some of the health indicators for African-American adolescent females as well. I will not go into all the details, but you can draw the conclusions. Health reform legislation is absolutely imperative if we are to truly eliminate the current health inequalities facing African-Americans and other people of color.

Inequalities are now well-documented by the premature death and disease rates among African-Americans. When Secretary Sebelius joined us at the press conference, she called these higher rates of premature death and diseases among African-Americans "quite stunning and shocking." She was very eloquent when she emphasized that, although we have become better at measuring these inequalities, we have made little progress in reducing them. She also pledged her personal commitment as well as that of the administration to eliminate such health disparities. These inequalities are serious and significant financial barriers that prevent access to quality health care services for the time sensitive treatment options to preventative care that are aimed at a wide range of chronic and debilitating illness.

QUESTION: I sit on the board of directors of Holy Cross hospital in Silver Spring, Maryland, part of the Trinity Health System. It is a non-profit hospital. Because of their tax-exempt status, not-for-profit hospitals are required to have community benefit programs. I know there are ninety different languages that are spoken by patients in Holy Cross Hospitals. I do not know that there are translators for all of those languages, but I do know that the commitment of the hospital and the health system is significant in providing as many translators as possible. Can we not use the traditional community benefit required by the IRS to coerce not-for-profit hospitals to provide these services as part of their commitment to community?

JULIA PIERCE: There are a number of laws like community benefit and Title VI, but the problem really is enforcement. Title VI, for example, is mostly enforced by the HHS Office for Civil Rights (OCR). We lack the resources to do what we need to do. To enforce community benefit, folks would have to bring challenges to the IRS when hospitals fail to meet community obligations.

QUESTION: One of my areas of interest is traditional health beliefs. In certain ethnic groups, there are traditional medicine beliefs that really affect receptivity to Western medicine. Is there any emphasis on that in your programs? And how is that being addressed?

JULIA PIERCE: There certainly is in the IHS program. I would have to restate that the majority of people working for IHS are Native Americans. There is a huge respect for native medicines. Each individual tribe has its own specific traditional medicine practices, ranging from sweat lodges to specific herbal remedies to practices that are completely unfamiliar to us. When we negotiate Indian Self-Determination Act contracts with the tribes to transfer the funding that IHS will spend, almost all of the contracts have a traditional medicine paragraph. This is something that we fought with the Department of Justice on for years, because the Department of Justice is very conscientious about litigation risks. It is the right thing to do to support people in their traditional practices.

MARA YOUDELMAN: This is a broad issue. You hear about cultural competency and trying to help educate health care providers about different cultural issues that come into play. I think it is more important to develop what is called cultural sensitivity or humility. We are never going to get providers to understand all of the different cultural issues of all the patients that they treat. Rather, they have to be understanding and receptive to talking with their patients about what those beliefs are and what those complementary alternative medicine practices are and how it may affect the patient's understanding of their diagnosis and decision about treatment, etc.

Language is one piece of the puzzle of cultural awareness, but it is certainly a much broader issue and it does affect disparities. Many patients will not follow through with a treatment plan because they do not understand it or is not explained to them in a way that they can be reconciled with their cultural beliefs.

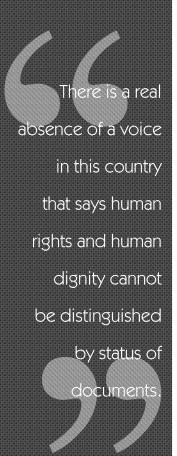
JULIA PIERCE: Additionally, it is important to know that traditional medicine is not the same as complementary alternative medicine. They are usually grouped together. They are not grouped together at the IHS.

QUESTION: There has been a lot of discussion surrounding immigration in the US, specifically illegal immigration. There has been an assumption that illegal immigrants are using up the system. Then there are many who have said that this is not the case. What does the research say?

MARA YOUDELMAN: There has actually been research in a number of settings that showed immigrants are actually using less health care, costing less to the health care system, and are on average healthier.

QUESTION: There is an association between language issues and immigration. How do you deal with that politically? If you want more funding or if you want legislation, how are you going to go against the anti-immigration political wall that I would think exists even if the Democrats are in power?

MARA YOUDELMAN: It has been interesting. We have been very cautious about how we talk about language access. We do not talk about immigrant issues and language access in the same Capitol Hill visit or policy discussion, because it does get tainted. As much as we want to advance immigrants rights, we realize if we are going to advance language access we have to be careful. But, we also can show based on the demographics and census data that there are lots of citizens, both nationalized citizens and U.S.-born citizens who are limited English proficient. This also applies to



many assylees and refugees who come into this country. We have been able to make the case that this is about access quality.

I was able to crunch some basic census numbers to find that about two thirds of LEPs are actually here as citizens or documented immigrants. We are not really talking about a huge proportion of undocumented immigrants. It is something in the arsenal that we can use to help make our case.

LEONARD RUBENSTEIN: You are raising the larger question of the poverty of our debate. During the presidential election, President Obama famously said that health care is a right. But, President Obama also went out of his way in a joint session of a Congress to say that undocumented people would not be in his health care plan. Everybody who is working

pragmatically to get health care reform has to buy into the notion that we are going to exclude undocumented people. There needs to be another voice. There is a real absence of a voice in this country that says human rights and human dignity cannot be distinguished by status of documents.

MARA YOUDELMAN: My organization has been trying to make that voice heard and we just keep getting deaf ears. We are having some success in states to get laws or amendments declaring health as a human right. If you buy into health as a human right, you do not have to talk about the immigrant issue. We are just meeting a lot of resistance from the policy-makers. We need louder voices from folks in higher positions whose voices will be heard.

- ¹ 31 U.S. (6 Pet.) 515 (1832).
- ² Available at www.jointcenter.org.