

# Closing the Gap

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## Working Toward Our Goal *Eliminating Racial and Ethnic Disparities in Health*

**Nathan Stinson, Jr., PhD, MD, MPH**  
Deputy Assistant Secretary for Minority Health

It has been one year since more than 2,000 of you came to Washington, D.C., to take part in an historic event—the first *National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health*.

We are undertaking a department-wide effort to address racial and ethnic disparities in health and have made the elimination of health disparities one of our top priorities.

We have many activities underway and more planned to help us reach our goal. The Leadership Summit was an important step, and I was happy to see so many people committed to ending health care disparities. These problems, however, cannot be solved simply by government. It will take the providers, the communities, the houses of worship—institutions and individuals across our society—working together to end disparities.

Building on the momentum from last year's conference, we continue to focus on six health concerns for communities of color today: infant mortality, cancer screening and management, heart disease and stroke, diabetes, HIV/AIDS, and child and adult immunizations. We also focus on factors such as access to health care and quality of health care. To tackle disparities, we have developed strategies that will require your support, if they are to be successful. Shortly after last year's conference, the Department, in partnership with the ABC Radio Networks, launched a national event—*Take A Loved One to the Doctor Day*—as a part of our *Closing the Health Gap* health education and information campaign for communities of color. The 2002 event was targeted primarily toward African Americans. More than 400 organizations, as well as elected officials and celebrities from across the nation, banded together to raise awareness of health disparities and encourage community action to get people to take a loved one to the doctor or another health professional.

This year, our partnership continues, and the campaign is now expanded to include American Indians and Alaska Natives, Asian Americans, Hispanics/Latinos, Native Hawaiians, and other Pacific Islanders. So, this year on September 16th, you are encouraged to organize a health event, attend a health event in your community, or help a friend, neighbor, or family member to take charge of their health by visiting a doctor, nurse, dentist, physician assistant, or other health professional. That's just one way you personally can help close the health gap.

In March 2003, Secretary Thompson convened a national health summit to call on all Americans to take the steps that will lead to a healthier nation. The *Steps to a Healthier US: Putting Prevention First* summit was attended by more than 1,000 community leaders, policy makers, health officials, and others. It laid out the Department's priorities and programs for *Steps to a Healthier US*, focusing attention on the importance of prevention and promising approaches for promoting healthy environments.

The Department also launched a new adult immunization initiative—Racial and Ethnic Adult Disparities in Immunization Initiative (READII)—to reduce racial and ethnic disparities in influenza and pneumococcal vaccination coverage for adults 65 years of age and older, focusing on African American and Hispanic communities.

In addition to our partnerships and prevention initiatives, HHS is putting additional resources into direct patient care. President Bush asked the Department to increase the number of community health centers across the country to reach individuals who lack access to quality medical care. As a result, HHS is expanding the current nationwide network of more than 3,300 health center

*Working Toward* continued on 2



sites that serve some 11 million low-income people, a large proportion of whom are from communities of color.

Many of the innovative ideas shared during the Leadership Summit and *Steps to a HealthierUS* are being implemented or supported by the Department.

Yet, to solve the crisis of health disparities, we need to continue to work collectively and think outside of the box. Each of us must work in our own communities to come up with real solutions to eliminate health disparities. It starts in our own homes with our own families and with a renewed sense of personal responsibility.

As promised, this expanded issue of *Closing the Gap* is the second and final part of our reporting on last year's Leadership Summit. I hope that you will find ideas in this issue that will stimulate further thinking and help advance your work on health disparities.

We at the Department of Health and Human Services will do our part to provide individuals, families, and communities with the resources they need to eliminate health disparities. Let me assure you we are committed to this effort and to undertaking the actions necessary to reach our goal.

Good health to all!

Nathan Stinson, Jr., PhD, MD, MPH  
Deputy Assistant Secretary for  
Minority Health



For more information on the National Leadership Summit to Eliminate Racial and Ethnic Disparities in Health, go to <http://www.omhrc.gov/summit> or call 1-800-444-6472.

Save the date...September 16, 2003 • Save the date...September 16, 2003 •

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*Closing the Gap* is a free newsletter of the Office of Minority Health, Office of Public Health and Science, U.S. Department of Health and Human Services.



The Office of Minority Health Resource Center provides free information on various health issues affecting U.S. minorities.

Send an e-mail to [info@omhrc.gov](mailto:info@omhrc.gov) to join our mailing list or to update your address. Or, write to OMHRC, P.O.Box 37337, Washington, DC 20013.

To submit story ideas or to comment on *Closing the Gap* articles, contact Brigette Settles Scott, MA, managing editor at the address above or e-mail [bscott@omhrc.gov](mailto:bscott@omhrc.gov).

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# Proud to be a Partner!

## *American Public Health Association Supports Doctor Day*

Georges C. Benjamin, MD, FACP

A man came into my emergency room once with a leg so discolored and swollen by gangrene that he had to be scheduled for an immediate amputation. "It used to hurt," he told me. "It doesn't hurt anymore, doc."

An elderly Black woman walked in with a large mass in her chest. She was diagnosed with advanced breast cancer, even as she denied anything was wrong.

One patient was wheeled in totally unconscious. His friend told us he had been drinking and urinating more than usual. After the medical team stabilized this man, he emerged from his diabetic coma and said, "A doctor told me a few years ago I had some 'sugar.'"

As an emergency room doctor, I have seen dozens of examples like these of people whose lives were put in danger by highly treatable conditions. Why? They didn't have a regular doctor. They received no preventive care. Indeed, they were so far removed from the health care system that they sought help only as their lives were at risk.

As the second annual *Take A Loved One to the Doctor Day* approaches, we as health care providers should take the opportunity to shine the light on the need for preventive care, especially among those hardest hit by cancer, HIV, diabetes, heart disease, and stroke. And the best way we can do that is by celebrating the relationship between patients, health care providers, and family members.

We know our greatest health disparities lie in minority and low-income communities, as well as vulnerable populations, such as senior citizens and people with disabilities. Why do 30 percent of Hispanics and 20 percent of Blacks lack a usual source of health care, compared to less than 16 percent of Whites? We know cultural and communication barriers are part of the problem. And we know the ones who can best break down those barriers are the people who live with and care for one another.

Eliminating racial and ethnic health disparities is one of our top three priorities at the American Public Health Association. Through

our, and so many others', efforts in recent years to wipe out inequalities in health care, we've learned that it takes a lot more than money or committees or task forces. It takes involvement at the community level: caring family members bringing their loved ones into clinics before problems become life-threatening.

We in the health care community never know when our efforts will bear fruit. Likewise, we might not know the individual lives we touch just by setting aside one day a year to remind people to take their loved ones to see a doctor. But I, for one, have no doubt that this very involvement makes a profound difference.

During my time as secretary of the Maryland Department of Health and Mental Hygiene, we started a Cigarette Restitution Fund program that used money from the tobacco settlement to fight cancer as well as smoking. Part of the program included a colorectal cancer screening.

A low-income Maryland resident was brought by her husband to the hospital emergency room with what seemed to her to be minor symptoms: blood in her stool and some slight abdominal bloating. At first glance, the likely diagnosis was hemorrhoids.

While in the waiting room, though, her husband read our program brochure and realized his wife most likely had colorectal cancer. He called the toll-free number. Even without health insurance, his wife received medical care less than a week later. Now, she's a cancer survivor.

We, as care providers, think about health all year long. It's the least we can do to set aside one day to stress the difference regular care can make in everyone's life. The APHA encourages you to tell everyone you know to take a loved one to the doctor on September 16<sup>th</sup>.

*Dr. Georges C. Benjamin is executive director of the American Public Health Association, the largest and oldest organization of public health professionals.*

*For more information, go to <http://www.apha.org> ♦*

### American Public Health Association

800 I Street, NW • Washington, DC 20001-3710 • 202-777-APHA (2742) • <http://www.apha.org>

The American Public Health Association (APHA) is the oldest and largest organization of public health professionals in the world, representing more than 50,000 members from over 50 occupations of public health.

- APHA brings together researchers, health service providers, administrators, teachers, and other health workers in a unique, multidisciplinary environment of professional exchange, study, and action.
- APHA is concerned with a broad set of issues including federal and state funding for health programs, pollution control, programs and policies related to chronic and infectious diseases, a smoke-free society, and professional education in public health.
- APHA actively serves the public, its members, and the public health profession through its scientific and practice programs, publications, annual meetings, awards programs, educational services, and advocacy efforts.

# Disparities Persist in Infant Mortality

## *Creative Approaches Work to Close the Gap*

Kauthar B. Umar, MA

During the last several decades, reducing infant mortality has been an ongoing challenge. The Centers for Disease Control and Prevention (CDC) states that despite substantial reductions throughout the United States, Black/White disparities in infant mortality rates persist. From 1980 to 2000, infant mortality rates declined 45.2 percent among all races, although the decline was greater for Whites (10.9 to 5.7 percent) than for Blacks (22.2 to 14.0 percent).

“Insufficient prenatal care resulting in low birth weight is a major factor associated with infant mortality,” said Dr. Fern Johnson-Clarke, chief of the Research and Analysis Division at the District of Columbia Department of Health (DCDoH). According to the DCDoH, in 2000, the percentage of low birth weight infants (those weighing fewer than 5.5 pounds) in the District was 11.9—with low birth weight affecting Blacks almost twice as much as Whites.

Yet, progress is being made through the DC Healthy Start Project. Initiated 10 years ago with funding from the Health Resources and Services Administration (HRSA), the project provides women with access to comprehensive prenatal care services they may not otherwise receive. “Women receive case management throughout the cycle—from pregnancy to delivery,” said Johnson-Clarke.

Since its inception, the DC Healthy Start Project has helped reduce infant mortality by 45 percent in the District. The Project, currently in its third phase of HRSA funding, has broadened its focus in various ways, and now includes outreach to fathers and prenatal depression screening. “As a result, since [the program began] none of the women who have participated in the Healthy Start Project have had an infant die from a preventable death,” said Johnson-Clarke.

### REACHing Out

Racial and Ethnic Approaches to Community Health (REACH) 2010 Project is a national demonstration project managed by the CDC that supports Healthy People 2010—the nation’s health promotion and disease prevention initiative. The primary objective of REACH 2010 is to help communities mobilize resources to support programs that eliminate the health disparities experienced by racial and ethnic minorities.

Through Michigan’s Genesee County Department of Health, the REACH Project in Flint takes a slightly different approach to reducing infant mortality. It works to improve the overall health status of women. In Flint, where the infant mortality rate of Blacks is about two and a half times that of Whites, the Department’s division director of Maternal and Child Health Services, Lillian Wyatt, has been working with the community. “One of the things we needed to do was to get the community involved in reducing infant mortality,” said Wyatt. “First, we needed to identify what the community al-

ready knew about infant mortality, what they thought was actually the cause of their babies dying, and areas where they thought they could help to solve the problem.”

In an attempt to fully engage the community and foster community mobilization, the REACH Project has developed three strategies: Community Dialog, Educational Training and Outreach, and Advocacy.

### Community Dialog

The dialog strategy brings representatives from across the community to discuss infant mortality, and to develop a community-based intervention aimed at reducing baby deaths. “To be truly effective in addressing infant mortality in the Black community, the project brings together groups that would otherwise not meet to address race and racism as they relate to infant mortality,” said Yvonne Lewis, executive director of Faith Access to Community Economic Development (FACED), a non-profit corporation that provides resources to low-income residents of Flint and Genesee County. “The dialog is a series of four sessions designed to bring 15 to 25 mothers, educators, and health professionals together,” said Lewis. “We engage the community. We ask the community questions like, ‘What is infant mortality? What are the causes?’”

Infant mortality is defined in the first session and its causes are identified in the second. Possible solutions are addressed in the third session, narrowed down to one idea, and then put into action by the fourth session. By meeting with health care providers and discussing the factors to high infant mortality rates in the Black community, some groups have been able to bridge the gap and work together to reduce infant deaths.

All interventions reinforce themes of cultural appropriateness and anti-racism. According to Lewis, the groups focus on how Blacks access health care services in the county, and embrace the notion that racial difference in infant death rates is a symptom of cultural, institutional, interpersonal, and internalized racism. Lewis maintains that this approach includes educating health care professionals about race, racism, and race-based privilege.

“One of our major hospitals didn’t have a real strong role in the African American community and a dialogue group that completed their fourth session decided to do interventions with physicians at that hospital,” said Lewis. “Physicians need to be a part of correcting the problem, so we introduced them to our Maternal and Infant Health Advocacy Support Services program.”

With an audience of obstetricians and gynecologists, the dialogue group discussed disparities in infant mortality and engaged the community in the solution. After discovering that physicians believed the real issue to be non-compliant patients, the dialog group decided



gettyimagesphoto/rubberball

to recruit physicians to participate in the FACED referral process.

“Group members provided an orientation to physicians on utilizing our referral process to get expectant mothers the additional support they may need during their pregnancy,” said Lewis. “The dialog group created this action plan one year ago, and today we have OB/GYN’s and primary care physicians in three hospitals involved in this particular referral system.”

### Educational Training

The Project’s Educational Training strategy assists the University of Michigan with cultural competency training of future health professionals, faculty, and staff. The African American Cultural Educational Awareness Center was developed to serve the community with health education in a similar manner.

Through an educational component called Black Unity and Spiritual Togetherness, men and women expecting children are paired with friends or family members labeled “birth sisters and brothers.” The partnership addresses cultural elements from a family perspective and provides education on healthy parental behaviors, which lead to healthy pregnancies, followed by healthy births and ultimately, healthy children. “All of us together have to work collectively on the issue,” said Lewis.

### Outreach and Advocacy

The Outreach and Advocacy strategy utilizes referrals from the Women, Infant and Children Program to identify women who are in the early stages of pregnancy or recently gave birth. Those mothers are then paired with maternal and infant health advocates, who offer support during the preg-

nancy and up to the child’s first year. Billboards, television, and radio commercials have also been developed to reinforce the message.

“We want that message to ring out loud and clear—babies don’t have to die,” concluded Lewis.

*For more information on the DC Healthy Start Project, contact Dr. Fern Johnson-Clarke, District of Columbia Department of Health at 202-442-9032. ♦*

*For more information on the Flint REACH Project, call 810-257-3194. ♦*

*For more information on Faith Access to Community Economic Development, e-mail Yvonne Lewis at yvonlewis@hotmail.com or call 810-232-7733. ♦*

*Disparities Persist in Infant Mortality is based on the Summit workshop “Promising Practices in Eliminating Health Disparities: Infant Mortality.”*

# Out of Many, One

## *Coalition Building for Minority Communities*

Kauthar B. Umar, MA

Can representatives from more than 80 diverse organizations work together toward one common goal? Some would say impossible. Yet, one such coalition has been successful in developing a national health agenda that is cohesive and unified in its approach to improving the health status of people of color.

In its conference report, *Out of Many One: A Multicultural Action Plan to Achieve Health Parity (OMO)*, developed in November 2000, representatives from a wide variety of minority health organizations including the National Latino Council on Alcohol and Tobacco Prevention, the Asian & Pacific Islander American Health Forum (APIAHF), the National Indian Council on Aging, Papa Ola Lokahi (POL), the Summit Health Institute for Research and Education (SHIRE), and individuals representing communities of color throughout the nation gathered to develop strategies to improving the health of minorities.

Partially funded by the Office of Minority Health, and in line with Healthy People 2010 objectives, the OMO plan provides a path for achieving health parity for communities of color within the next decade. The OMO's goal and underlying philosophy is to empower each racial and ethnic community by developing and implementing a united health agenda. That agenda focuses on common health issues, while respecting the differences among communities of color.

"As we've moved from one stage to the next, our coalition [OMO] has always been equally distributed among all racial and ethnic groups," said Ruth Perot, executive director of SHIRE. "It's very easy to bring to the table the token Black, the token Asian American, the token Hawaiian, the token Indian and consider it done. We said no. As we moved forward in this process, our management committee had one person from each group go out and get three more people from their group to add to it. At all times, we had equity and balance. If we want people to feel



Connecting or linking with one another through circles and other means is important in all communities of color. Symbolizing that interconnectedness, Summit attendees tie ribbons onto the 'Rope of Hope'.

that they have an equal voice, we have to provide an equal avenue for their participation," Perot said.

Lack of access, resources, political power, and policies were identified by the OMO management committee as barriers to health parity—which can discourage those who are searching for change from expecting any glimmer of hope. Colonialism, racism, oppression, and pessimistic attitudes within communities of color were also identified as barriers to progress.

### Goals and Objectives

After analyzing the barriers, six goals were developed by the OMO coalition:

- ❖ Achieve universal health care;
- ❖ Establish comprehensive health systems;
- ❖ Improve cultural, institutional, and educational development;
- ❖ Improve research data;
- ❖ Achieve empowerment; and
- ❖ Develop community leadership.

Ultimately, to reach health parity, the coalition believes that several public health objectives must be realized:

- ❖ Increase insurance coverage;
- ❖ Institutionalize cultural competency training;
- ❖ Research and assess cultural healing traditions; and
- ❖ Increase funding for research conducted by minorities on minorities.

These objectives affect the way in which communities of color respond to health care in the U.S. "I think what we want is for our health to be the best it can be. Whatever the Jaguar [luxury vehicle] quality of care is, whatever the Jaguar outcome is, that's what we hope to get," said Gem Daus, legislative and governmental affairs coordinator for APIAHF. According to Daus, achieving the best health potential must begin by receiving health care that is equivalent to the best level of care available. "There must be parity of health systems. This can only be achieved by delivering culturally-based, appropriate, comprehensive, holistic, fully-funded, sustainable,

*OMO continued on 7*

and community-based services that foster prevention and quality of life,” said Daus.

Michael Bird, executive director of the National Native American AIDS Prevention Center and the immediate past president of the American Public Health Association, stresses that such a model should be supported and spread across the nation, teaching fairness, equity, democracy, and justice.

To ensure these qualities, emphasis is placed on community involvement and empowerment. By establishing community Institutional Review Boards (IRB) in communities of color, the OMO coalition suggests that power shifts from the universities and scientists towards communities, so they too have an equal say. When planning the Native Hawaiian Health Care System’s IRB, Joanne Tsark, research director of POL, said community members actually outnumbered the scientific representation on the board.

“In a room filled with businessmen, researchers, and scientists, a cow farmer from the island of Maui, who may have never heard of an IRB, is also on the board and encouraged to speak as a farmer, simply because of his concerns,” said Tsark.

“Our community members have the strongest voice,” Tsark continued. “If they disagree with anything, research does not move forward. We need to address every issue that the community member has on our IRB. There are parallels to the process we used in starting an IRB, to the process that the OMO coalition used in forming. We are going to be heard first. Not only are we the community at the table, but OMO built the table. We built the table for what we needed. We invited the people and everyone has a voice here.”

That voice, as OMO discovered, is unanimous. Quality health-care for all.

For more information on the *Out of Many, One: A Multicultural Action Plan to Achieve Health Parity*, go to <http://www.outofmany1.org> ♦

### Out of Many, One Founding Member Organizations

**American Public Health Association (APHA)**  
<http://www.apha.org>

**Asian & Pacific Islander American Health Forum (APIAHF)**  
<http://www.apiahf.org>

**National Indian Council on Aging (NICOA)**  
<http://www.nicoa.org>

**National Latino Council on Alcohol and Tobacco Prevention (LCAT)**  
<http://www.nlcatp.org>

**National Native American AIDS Prevention Center (NNAAPC)**  
<http://www.nnaapc.org>

**Papa Ola Lokahi (POL)**  
<http://papaolalokahi.8m.com>

**Summit Health Institute for Research and Education (SHIRE)**  
<http://www.shireinc.org>

*Out of Many, One: Coalition Building for Minority Communities* is based on the Summit workshop of the same name.

## This Site’s For You

### *Honoring Asian Pacific American Heritage Month*

“Asian Americans, Native Hawaiians and other Pacific Islander (AAPI) communities are affected disproportionately by cardiovascular disease, cancer, hepatitis B, tuberculosis, and other diseases,” said U.S. Department of Health and Human Services (HHS) Secretary Tommy G. Thompson during Asian Pacific American Heritage Month in May 2003.

In honor of the month, Secretary Thompson launched two new health Web sites directed at AAPIs. These sites expand on the Department’s *Steps to a Healthier US* initiative which underscores the President’s call to action for healthy lifestyles through public awareness of disease prevention efforts. “At HHS, we’re increasing our online presence to bring culturally relevant and appropriate health information and services to their fingertips,” said Thompson.

Available at HHS’ consumer-oriented healthfinder® Web site—<http://www.healthfinder.gov/justforyou>—multilingual information in Cambodian, Chinese, Hmong, Korean, Laotian, Samoan, Thai, Tongan, and Vietnamese will be useful to caregivers, patients, and others searching for health information on behalf of individuals more comfortable in their native language.

Complementing the new healthfinder® section is “Asian American Health,” a companion Web site launched by the National Institutes of Health’s National Library of Medicine.

Found at <http://asianamericanhealth.nlm.nih.gov>, the site features census data on major Asian American populations, background on cultural traditions and heritage, links to health policy offices, online medical databases, publications, and other organizations.

For more information on *Asian American, Native Hawaiian and other Pacific Islander health and data*, go to <http://www.healthfinder.gov/justforyou> or go to <http://asianamericanhealth.nlm.nih.gov> ♦

### American Indian and Alaska Native Web Site

Information specifically targeting American Indians and Alaska Natives is also available at <http://www.healthfinder.gov/justforyou>. The Office of Disease Prevention and Health Promotion, which manages healthfinder®, has partnered with the Office of Minority Health, the Indian Health Service, and a host of other organizations to improve the delivery of health information to American Indians and Alaska Natives.

A report detailing lessons learned from extensive interviews and usability tests in Alaska, Arizona, and Colorado can be found at <http://odphp.osophs.dhhs.gov/projects>.

We welcome your suggestions for continuing to improve the site. Send feedback to [healthfinder@nhic.org](mailto:healthfinder@nhic.org) ♦

# Project IMPACT

## *Increasing Minority Participation and Awareness of Clinical Trials*

Brigette Settles Scott, MA

Research in the past few decades has uncovered significant differences among population groups in the metabolism, clinical effectiveness, and side effects of many prescription medications. The lack of information to support appropriate pharmaceutical interventions in minority patients further contributes to health disparities among people of color. Equally as important are the documented environmental, biological, cultural, and psychosocial factors which affect a patient's ability to comply with drug regimens.

"Until recently, there was no significant effort by the Food and Drug Administration to have the data that come out of clinical trials representative of the society," said Dr. Michael A. Lenoir, principal investigator for the National Medical Association's (NMA) Project IMPACT (Increasing Minority Participation and Awareness of Clinical Trials). "There are a number of studies that look at polymorphisms [naturally occurring variations in how individuals metabolize medications] and responses to medications in different ethnic groups. There is a clear distinction between how certain groups are represented by polymorphic gene pools, and how they respond to certain medications. So, consequently, most medications released in this country have never been studied adequately in minority populations, particularly African Americans."

While it is always important to talk about the preventive aspects of health promotion and disease management—early detection and early intervention—Lenoir maintains that pharmaceutical treatment is often the first line defense in minority communities because of traditionally later diagnosis and more chronic complications from various diseases.

"Often, treatment simply comes down to the medications. Currently, there is no equitable information about what effect medicines have on our people. I think it is important to ensure that pharmaceutical products, which are released for distribution to minorities, are adequately studied in the populations that represent them. We must ensure that when a drug comes to market, and people start to take it, they can be assured that it has been representatively studied in all populations," said Lenoir.

### **Making an IMPACT**

The NMA has taken on a major effort to get more minority participation in clinical trials. Initially funded through a cooperative agreement with the Office of Minority Health (OMH), the goal of Project IMPACT is to increase knowledge and understanding, and to raise awareness about clinical trials among African American physicians and consumers, thereby increasing their participation in all aspects of clinical research.

"Our objective initially was to simply educate and train physicians to become clinical investigators because it's difficult to get people

into clinical trials unless they trust the people who are doing it," said Lenoir. "We've since expanded our program to educate African American patients about the value of participating in clinical trials," he added.

Education and training programs are the cornerstone of the project's activities. Project IMPACT has three core programs designed to teach minority physicians and other health care providers about clinical research, its benefits, and reasons why participation is important for African Americans. The training includes a one-hour presentation, *Clinical Research/Trials in Brief*; a half-day workshop, *Clinical Research Overview and Training*; and a three-day intensive investigator course, *Good Clinical Practices*.

According to Lenoir, Project IMPACT trained more than 500 doctors from across the country during the last five years. "We've provided information on ethics, regulations, what's involved in becoming a clinical researcher, and what resources are needed to do effective clinical trials. So now, we have a database of physicians who are able to talk rationally to their patient populations about clinical trials," Lenoir said.

"We also created consumer-based materials, including a great book, called *You've Got the Power: What You Should Know about Clinical Trials*. We distributed it as far as our resources have permitted to our physician base and large African American organizations," Lenoir said. "Literacy is an issue for many Americans, so we also use a lot of media tools to talk about clinical trials. We also have ambassadors, who are prepared to go and talk to community groups around the issue of clinical trials," he added.

"It is our intent to engage in an honest dialogue locally and nationally with the African American community," Lenoir continued. "We need to discuss in a rational way what clinical trials are and what the advantages and disadvantages are, so that we provide a more balanced perspective. We don't want the narrow perspective that we got from our experience with Tuskegee and other studies," said Lenoir.

As a result, Project IMPACT now reaches more than 1,000 health care providers and consumers. It introduces them to the clinical research process, and the value of participation in clinical trials. In total, the Project conducted 19 clinical trials and developed and disseminated several consumer-directed educational brochures, videos, and fact sheets.

In the future, Project IMPACT will interview the physicians who participated in the training program, but did not take part in a clinical trial to determine what the barriers are and how to overcome them. Ultimately, NMA hopes to expand the base of African American physicians who conduct clinical trials, and enroll more of the patients that they serve.

*IMPACT* continued on 9

### Grassroots Effort

The Bay Area Multicultural Clinical Research and Prevention Center, located in Oakland, Calif., was founded by Lenoir to incorporate people of color in clinical research trials. The Center consists of a team of primary care and specialist physicians from within the African American community, who assist in the recruitment of patients, and serve as investigators to clinical trials.

There are very few African American investigators at the local level, where most of the research is conducted. Lenoir believes that this disparity is a “clear violation of the scientific process.” He argues that if African American participation in clinical research does not increase, the impact on the community at large will be enormous.

“Clinical trials are hard to do. You must be organized to do them. We are gradually getting more and more of our doctors to participate,” Lenoir said. “We’ve certainly been successful in engaging the community on a number of different levels about clinical trials,” Lenoir continued. “We’ve developed four investigators in this area, and have done 10 successful clinical trials. One of our major contributions to the trials has been African American participation. When the trial is finished, African Americans will be represented in the trial’s results.”

However, these numbers are not enough. Lenoir believes that minority groups need to be more involved in clinical research if racial and ethnic disparities in health are to be eliminated. Educating physicians and helping the African American community understand both the advantages and disadvantages of clinical trials is a small step that has far-reaching implications.

“We are continuing to get more people interested in clinical trials, and we’re working diligently to get physicians interested in not only serving as investigators, but developing their own clinical trial programs,” concluded Lenoir.

*For more information on Project IMPACT, call 202-347-1895. ♦*

*For more information on the Bay Area Multicultural Clinical Research and Prevention Center, call 510-834-4897. ♦*

*Project IMPACT is based on the Summit workshop “Minorities in Research: Its Impact on Health Disparities.”*

## Start ‘Em Early, Start ‘Em Young

### *Introducing Minority Youth to Health Professions*

Brigette Settles Scott, MA and Kauthar B. Umar, MA

Health care providers play a critical role in keeping communities healthy. The lack of minorities in the health field is a significant public health issue. Fewer minorities often mean that racial and ethnic minorities receive unequal treatment, thereby contributing to higher morbidity and mortality rates from chronic diseases. Culture and language are fundamental factors in how health care services are delivered and received. There is an overwhelming need to increase the number of physicians—particularly physicians of color—who can effectively communicate both linguistically and culturally with their patient base.

Many experts believe that the key to expanding the number of minority health care professionals lies in improving the education system and introducing minority youth to opportunities in the health field during the formative years—ultimately leading to more minorities entering the health professions.

“The student body at medical schools lacks minorities and that’s not what we want,” said Dr. William A. Robinson, director, Center for Quality and chief medical officer, Health Resources and Services Administration. “We know that the school experiences for minority children are not what they need to be. In many instances minority children are still going to separate or unequal schools, and this affects students regardless of whether they are African American, Hispanic, Asian, or American Indian.”

Students, regardless of race and ethnicity, face pressures each day which act as barriers to academic success. However, Robinson adds that many minority students have to jump additional hurdles in order to succeed.

“If we don’t deal with the psychosocial issues in our community, we are wasting our

time thinking that our numbers [in the health field] are going to be increased,” said Marilyn Johnson of the National Public Health Forum in Columbia, Md. “First of all, we have to have parental support, and unfortunately, we have a lot of parents that are just struggling to survive,” she added.

Johnson said many people have a vague idea of what it takes to make it in today’s world. “People have no concept of what it takes for their children to go to college, better yet, to be a doctor or an allied health professional,” she said. “It’s just not heard of—to be a scientist and to conduct research at NIH,” she added.

According to Johnson, several issues prevent students from feeling confident and being prepared academically to enter the health field, such as lack of positive parental influence, peer pressure, low self-image, lack of academic guidance, and inadequate preparation for tests.

While students in affluent school districts are being “programmed” to pass standardized exams like the SAT, minority students in poor school districts are often considered to be “doing well” if they simply pass on to the next grade, Johnson said.

### Aspiring Youth

By addressing the educational problems facing minorities before they reach college, programs like ASPIRA are able to influence youth to pursue fields such as science, math, and health. “The success rates of minority youth will rise, particularly if there is a collaboration among the community and the parents,” said Hilda Crespo, vice president for public policy at ASPIRA Association, Inc., headquartered in Washington, D.C.

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*“The student body at medical schools lacks minorities and that’s not what we want...”*

Dr. William A. Robinson

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*Start ‘Em Early continued on 18*

# You Too Can Save a Life

## *Encouraging Minorities to Become Donors*

Kauthar B. Umar, MA

Since its inception in April 2001, the *Gift of Life* Donation Initiative has proven to be a winner. This five-part national program was developed by the Administration to increase awareness and promote donation of organs, marrow, and tissue for transplantation, as well as blood donation. Although there has been marked improvement in organ donation over the last several years, much more work remains to be done.

Speaking in August 2002 on National Minority Donor Awareness Day, Health and Human Services (HHS) Secretary Tommy G. Thompson said the *Gift of Life* initiative led to a seven percent increase in overall donations over the past year and a 13 percent increase in African American donors. Hispanic donations accounted for a 14 percent increase. But, according to Secretary Thompson, a more concerted effort remains and these efforts should be directed toward minority communities.

“Because of this marked increase in donors, and because of someone’s selfless act of love and compassion, an additional 1,000 people who needed transplants last year [2001] received them,” Thompson said. “However, we need to continue to reach minority communities with the message that organ donation saves lives,” he added.

In addition to reaching out to the minority communities, a Federal/private partnership was created to help involve employers and their employees. Under the *Gift of Life* Donation Initiative banner, Secretary Thompson mobilized the resources and expertise of the Federal government, the private sector, and local communities in what is known as the *Workplace Partnership for Life* program. This feature involves collaboration with companies and employer groups of all sizes to make information on donation available to employees.

### The Problem

There are currently more than 80,000 people waiting for organ transplantation in the United States, and between 20,000 and 30,000 people are diagnosed each year with blood diseases that require marrow donation. According to HHS, about 63 people each day receive an organ transplant, but another 16 people on the waiting list die because not enough organs are available. Compounding matters, minorities are disproportionately underrepresented among available donors—making the survival rate for minorities in need of transplants quite low.

“About 54 percent of those on the waiting list are White, 26 percent are African American, 15 percent are Hispanic, and 5 percent

are Asian,” said Lynn Wegman, director of transplantation, Health Resources and Services Administration (HRSA). “The largest proportion of patients on the waiting list (52,000) are waiting for a new kidney. About 38 percent of those are African Americans, because they are transplanting at a lower rate.”

However, a shortage of minority donors has made it difficult to locate the best matches, and contributes to longer waiting periods for transplants for minorities. Tissue types are inherited, much like hair or eye color. Matching organs between members of the same ethnic and racial group often enhances successful transplantation. Patients are less likely to reject a kidney if an individual who is genetically similar donates it.

### Barriers to Donation

While African Americans have one of the greatest needs for organ and tissue transplantation, they are often reluctant to become donors. Dr. Jeffrey Chell of the National Marrow Donor Program (NMDP), a non-profit organization based in Minneapolis, Minn., says that there are barriers to transplantation for the general public, however, when race becomes a factor, barriers grow even more. “There are a number of barriers that exist that limit a patient’s access to a transplant. Those barriers differ by racial group. Race matters in transplantation,” said Chell. “The first barrier faced by everyone is having a match and having that person available. Next is access to transplantation. There are economic and sometimes geographic barriers. Both are hardest for minorities in the U.S.”

Misinterpretation of the organ donation process and a lack of knowledge are additional barriers, according to Chell. Mistrust of the medical system and a fear of not receiving appropriate medical treatment are also cited as reasons why many minority families decline donation. Religious and cultural beliefs are additional factors, especially the belief that the body must remain intact after death. Asian Americans, Native Americans, African Americans, and Hispanics have individual cultural and religious beliefs that may deter some families from donating.

### Organ Procurement

HRSA plays an instrumental role in funding and overseeing Federal efforts to improve the national system of procuring, distributing and transplanting organs, tissue, bone marrow, and blood stem cells. President Bush’s fiscal year 2003 budget included nearly \$25 million,

“Dying from needing an organ is preventable.”

Paul Schwab, executive director, Association of Organ Procurement Organizations.

an increase of \$5.2 million, for HRSA's organ procurement and transplantation efforts. The requested level is targeted to increased efforts to encourage organ donation and education.

The United Network for Organ Sharing (UNOS) administers the nation's only Organ Procurement and Transplantation Network (OPTN). It collects and manages data about each transplant event occurring in the U.S., facilitates the organ matching and placement process, and oversees the national waiting list. In addition, UNOS links all transplant centers and organ procurement organizations (OPOs). OPOs are responsible for approaching families about the option of donation when they have lost a loved one. OPOs evaluate the medical suitability of potential donors, coordinate the recovery, preservation, and transportation of organs donated for transplantation, and educate the public about the critical need for organ donation.

The LifeCenter Northwest Donor Network of Bellevue, Wash., the largest organ procurement organization in the U.S., says cross-racial donations can, and do, occur successfully when the matches are available. Genetic makeup is a crucial factor when matching a specific donor and recipients. As a result, an individual of Hispanic descent may match better with an organ from another Hispanic versus a different racial or ethnic group.

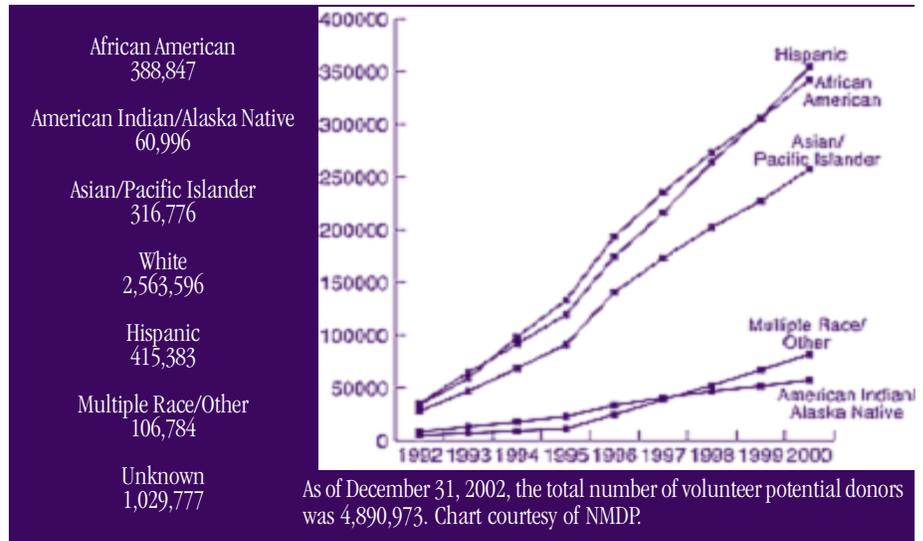
In addition, organ donations can be collected from both the deceased and the living. "Last year, there were 6,500 living donors in this country. For the first time, the number of living organ donors surpassed the number of deceased organ donors," said Wegman. "Living organ donors are traditionally relatives or friends of the organ recipient, making the donors more inclined to donate because the recipient is a loved one," she added.

Wegman further mentioned that there were nearly 6,100 deceased donors in 2002. Despite the surprising increase in living donors, the disparities in terms of race and ethnicity were equally as shocking as they were for deceased donors. Seventy to 72 percent of living donors are White, 12 to 13 percent are African American, and another 12 to 13 percent are Hispanic.

### Increasing Minority Donors

There are a number of national programs and initiatives created to break down the bar-

## National Marrow Donor Program Registry Growth



riers and make donations easier and more attractive to minorities. NMDP has developed a strategic approach to increase the number of transplants, improve transplant outcomes for patients, and in particular, service the needs of minority patients. The initiative addresses racial disparities and revolves around recruitment, education, patient advocacy, research, and NMDP organizational diversity.

In 1993, NMDP developed a series of initiatives to address recruitment in minority communities. Programs like, *African Americans Uniting for Life, Keep the Circle Strong for American Indians and Alaska Natives, Asian Pacific Islander Donors Can Save Lives*, and *Hispanics Giving Hope* were remarkably successful and several components of these initiatives continue today.

"Each of these programs was developed with direct involvement and consultation from people in those communities," said NMDP's Isaac Fordjur, legislative representative. "The programs also included the development of very culturally centered materials that were translated into the proper languages. A team of what we call ethnic marketing associates helps make sure that NMDP is addressing the needs of the community in terms that the community can appreciate," added Fordjur.

NMDP has also developed a series of recruitment groups that work with NMDP donor centers across the country. In these groups are individuals who are involved and highly visible within their communities and work to recruit donors to the registry. Language assistance is available in 26 different

languages, and written materials are available in six languages.

Projects at Historically Black Colleges and Universities (HBCU), in collaboration with African American fraternities and sororities, have also worked well for NMDP. "The *Touchdown for Life* campaign which is sponsored by 3M Corporation, in partnership with our donor centers, recruits about 6,000 donors a year to the registry on HBCU campuses," said Fordjur. The Asian Pacific American Medical Student Association recently finished a campaign that recruited approximately 3,500 donors. In addition, Mu Kappa Alpha, a national Hispanic fraternity, recruited approximately 3,000 donors in 2002.

Working with students and universities to address the need for donors in minority communities has also proven to be a sound tactic for the National Minority Organ Tissue Transplant Education Program (MOTTEP).

In 1991, Dr. Clive O. Callender, chairman of the Department of Surgery at Howard University Hospital, helped develop the first minority-directed dialysis and transplant center, and histocompatibility and immunogenetic laboratory in the U.S. He envisioned an organization that would target minorities and educate them on the importance of organ donation while encouraging them to become donors. This was done using a grassroots effort—an endeavor that had not been used in targeting minorities in the past. Just three years later, the official MOTTEP office was

*Organ continued on 19*

# Health Care Headaches

## *Accessing Safety Net Services*

Kauthar B. Umar, MA

The health care safety net—the Nation’s system of providing health care to low-income and vulnerable populations—was recently described by the Institute of Medicine as “intact but endangered.” Federal budget cuts and an unstable economy have impacted the delivery of health services to urban communities of color throughout the United States. Safety net services, such as those provided by public hospitals, free clinics, and private physicians, are accessed largely by minorities according to Dr. Thomas P. O’Toole of Johns Hopkins Urban Health Institute. Despite the critical need for these services, barriers are preventing access and posing a serious problem for many minority communities in need.

“Barriers to safety net services cannot be taken lightly,” said O’Toole. “Lack of access for those most in need is a life-threatening event and it can not be tolerated. Barriers to care need to be treated as a civil rights violation. You need to keep the focus on the individual, their family, and the community in developing social supports so that we can truly move beyond the rhetoric and see to it that no one gets left behind.”

According to O’Toole, the struggles surrounding safety net services affect both providers and patients in urban communities all over the country. In the city of Baltimore, Md., a quarter of the population lives below the poverty level, and the life expectancy rate is seven years below that of the national average. O’Toole says these statistics are more pronounced among African Americans and other minorities who are actively utilizing safety net services, and suffering when they are no longer available.

In a 2001 survey, *Inside Baltimore Safety Nets*, conducted by Soros Service Program for Community Health, safety net sites were defined as “those facilities where there’s an explicit policy of providing care and services regardless of one’s ability to pay.” Of the 250 surveyed clients recruited from eight safety net sites, 83.5 percent were African American, 65 percent were male, 42 percent were homeless, and 40 percent reported to be HIV positive.

The surveyed clients identified 168 safety net sites that they utilized in Baltimore. Sites ranged from traditional health care providers to homeless shelters. “When asked what would happen if these sites were not available? One in four respondents reported that they would be homeless, relapse back into drug use, be without care, or be dead,” said O’Toole.

Site directors reported that a mere 10 percent cut in Federal funding would result in a 20 percent staff reduction and a 10 to 50 percent service reduction. It is clear, according to O’Toole, that not only are these services fragile and vulnerable to the changes in the Federal and state budgets, but they represent the link between adequate health care and survival for many minorities.

More than half of the sample reported having difficulty accessing care services like dental care, primary care, obtaining prescription drugs, and accessing specialty care. One in four of the clients surveyed were unemployed, and those who were employed, were making on average \$12,500 per year. For two out of three respondents, the principle reason for lack of access was cost and lack of insurance. Sixty percent surveyed had no health insurance.

### Leaving People Behind

“We have this myth that folks who don’t have insurance aren’t working,” said Kathleen Stoll, associate director of health policy analysis, Families USA, in Washington, D.C. “In fact, eight out of ten of all uninsured people in this country, work. Their jobs don’t offer health insurance benefits, so they and their family members end up uninsured.”

According to Stoll, being uninsured is a problem, especially for people of color. In a 2002 study, the Center for Studying Health Systems Change reported that the impact of being uninsured is actually greater on people of color than on Whites. “People of color are at least twice as likely to be uninsured as Whites, largely reflecting lower rates of private, employer-based coverage,” Stoll said. She added that they work lower wage jobs, struggle to make the health insurance premiums, and end up not being able to afford coverage.

Since employers appear to be ignoring low-wage workers, Stoll indicated that Medicaid is expected to “fill in the gap,” but often times does not. While Medicaid successfully serves many people of color, disproportionately, people of color have to rely on Medicaid. Many find it as an inadequate safety net service. As the Federal government provides some broad guidelines regarding Medicaid, states set up their own eligibility levels, determining who is poor enough to receive services. Within the system, children are favored most and almost all low-income children in all states are covered under the State Children’s Health Insurance Program (SCHIP). Stoll says it is the parents that are unfortunately being left behind.

“If a parent takes their child into the doctor, the doctor can see the kid but if mom’s sitting in the waiting room, and she’s sick, she can’t see the doctor,” said Stoll. Often, children of women in low-income families get the care that they need, but their mothers are unable to get care for themselves.”

State eligibility levels make it difficult for many parents working low-wage jobs to receive Medicaid services. Stoll says, in 26 states if you work full time, at minimum wage, and you are a parent, you are not eligible for Medicaid. These services, remain unattainable for many. Some parents see the individual health insurance market as another

*Health Care Headaches* is based on the Summit workshop “Access to Safety Net Services.”

option. According to Stoll, this type of insurance is only an option for those “who are in perfect health,” often denying people with health concerns. With inadequate maternity coverage, women in particular, do not benefit or view this as a sound option.

### Alternative Safety Net Services

With traditional safety net services dwindling, alternate safety net options are being provided on the grassroots level. Twelve years ago, Dr. Jim Withers, an internal medicine physician, began providing medical care to the unsheltered and transient homeless population on the streets of Pittsburgh, Pa. Inspired by his exposure to “street medicine” in some of the poorest parts of Latin America, Withers, along with formally homeless man Mike Sallows, dressed as homeless, and began to make nighttime street rounds throughout the city. As people from all walks of life started to volunteer, Operation Safety Net (OSN) was born, with Withers as founder and medical director.

Today, the organization is recognized as one of the Nation’s first targeted, full-time, street medicine safety net programs, serving a population of mainly African American males between the ages of 22-50. Hosted by Mercy

Hospital, and in partnership with over a dozen soup kitchens and shelters, OSN provides direct health care to individuals on the streets.

With a current yearly budget of \$300,000 from Allegheny County’s Department of Human Services, the state Department of Public Welfare, and numerous awards and grants, OSN serves more than 14,000 homeless annually. OSN teams consist of former homeless people, volunteers, clinicians, and medical students who provide patient services in their own environments, where they feel most comfortable.

“We make medical rounds on the streets, instead of hospital floors,” said Linda Sheets, program administrator at Mercy Hospital. “We don’t demand that these individuals come to area clinics, we don’t ask too many questions, and names are optional. We try to build trust over several visits. While we don’t feel that this is the best answer for health care and prefer that they have a primary care physician, we feel that with trust we can help them get to that point. We measure our success by the number people we provide care for and the number of volunteers we recruit. When OSN began we had only one street team and today we have 16.”

Sheets says OSN became the only op-

tion for many who have seen traditional safety net services and programs close. She says that OSN provides HIV and hepatitis tests and immunizations. A large number of the patients OSN treats have chronic lung problems, podiatry problems, mental health issues, drug and alcohol addiction, and hypertension.

OSN began by providing health care from an old bread truck. Today, they use an upgraded van equipped with x-ray equipment. Sheets says the vehicle allows patients the opportunity to build trust with the staff, and also become a social center for the homeless community—although care remains primarily on the street.

“The lesson is to work as a team. You listen to the patient and understand the goal is to provide them with the best direct care possible,” Sheets said.

*For more information on Operation Safety Net go to <http://www.operationsafetynet.net> or call 412-232-5739.* ♦

*For more information on Medicaid, go to <http://cms.hhs.gov/medicaid/> or call 877-267-2323.* ♦

*For more information on the Soros Service Program for Community Health, go to [http://www.soros.org/baltimore/about\\_health.htm](http://www.soros.org/baltimore/about_health.htm) or call 410-234-1091.* ♦

## A Glimpse at the Uninsured

- ☒ An estimated 14.6 percent of the population or 41.2 million people were without health insurance coverage during the entire year in 2001.
- ☒ The percentage of people covered by employment-based health insurance dropped in 2001, from 63.6 percent to 62.6 percent.
- ☒ The percentage of people covered by government health insurance programs rose in 2001, from 24.7 percent to 25.3 percent, largely from an increase in the percentage of people covered by Medicaid (from 10.6 percent to 11.2 percent).
- ☒ In 2001, 11.7 percent of all children—8.5 million—were uninsured.
- ☒ The uninsured rate declined in 2001 for Hispanic children from 25.3 percent to 24.1 percent. The uninsured rates for non-Hispanic White children (7.4 percent), Black children (13.9 percent), and Asian and Pacific Islander children (11.7 percent) were unchanged from 2000.
- ☒ While most children (68.4 percent) were covered by an employment-based or privately purchased health insurance plan in 2001, nearly one in four (22.7 percent) were covered by Medicaid.
- ☒ Black children had a higher rate of Medicaid coverage in 2001 than children of any other racial or ethnic group—38.3 percent, compared with 34.9 percent of Hispanic children, 18.0 percent of Asian and Pacific Islander children, and 15.3 percent of non-Hispanic White children.

Source: Health Insurance Coverage: 2001, U.S. Census Bureau. Note: Because Hispanics may be of any race, data in this report for Hispanics overlap slightly with data for the Black population and the Asian and Pacific Islander population.

## American Indian/Alaska Native *Census 2000 Facts*

- ❖ There are 281.4 million people in the United States;
- ❖ 4.1 million (1.5 percent) reported themselves to be American Indian/Alaska Native;
- ❖ Of the 4.1 million, 2.5 million reported to be only American Indian/Alaska Native and 1.6 million reported being American Indian/Alaska Native as well as one or more races;
- ❖ 43 percent of American Indians live in the West; 31 percent live in the South; 17 percent live in the Midwest and 9 percent live in the Northeast;
- ❖ California has the largest American Indian population with 627,562;
- ❖ Oklahoma has the second largest American Indian population with 391,949;
- ❖ The largest tribal groupings are Cherokee, Navajo, Latin American Indian, Choctaw, Sioux, Chippewa, Apache, Blackfeet, Iroquois, and Pueblo;
- ❖ Eskimo was the largest Alaska Native tribal grouping followed by Tlingit-Haida, Alaska Athabaskan, and Aleut; and
- ❖ The population of American Indians/Alaska Natives is expected to reach 2.2 million by July 2006 and 2.4 million by 2015.

Source: *The American Indian and Alaska Native Population, Census Brief 2000*. To download the brief, go to <http://www.census.gov/prod/2002pubs/c2kbr01-15.pdf> ◆

## Indian Health Service Continues to Provide for Millions *Medicare and Medicaid Work Hard to Keep Up*

Brigette Settles Scott, MA

According to recent U.S. Census data, more than 60 percent of the American Indian population is geographically located in poor urban or rural communities off the reservation. Many American Indians do not have access to, and in many cases, are not eligible to participate in an Indian Health Service (IHS) sponsored health care program because they reside outside of the IHS service area.

IHS, an agency within the Department of Health and Human Services, is responsible for providing Federal health services to American Indians and Alaska Natives. The provision of health services to members of federally recognized tribes grew out of the special government-to-government relationship between the Federal government and Indian tribes.

The IHS is the principal Federal health care provider and health advocate for Indian people, and its goal is to raise their health status to the highest possible level. The IHS currently provides health services to approximately 1.5 million American Indians and Alaska Natives who belong to more than 557 federally recognized tribes in 35 states.

"In these communities, the unemployment rate is high. This situation gives American Indians who are not covered by the IHS few health care choices or alternatives," said Greg Richardson, executive director, North Carolina Commission on Indian Affairs.

"American Indians who are not covered by

IHS programs must fend for themselves, and as a result, are often not being seen by a doctor or not being diagnosed and treated for diseases," said Richardson.

Like most indigent, unemployed, or disabled Americans, some American Indians have access to treatment or health services through

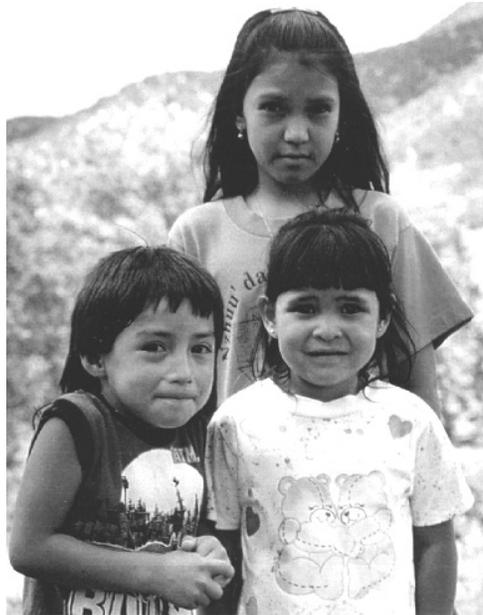
various government programs like Medicare and Medicaid. However, thousands of American Indians do not qualify for government-sponsored health care programs because they either work part-time, or work in temporary or seasonal jobs.

So, where do American Indians who are not covered by IHS go for health care? "In short, these American Indians must rely on private employers who provide health insurance, or if they are unemployed or economi-

cally disadvantaged, they must rely on publicly funded programs for their health services," explained Richardson.

"Another issue that needs to be addressed is that IHS services are not portable and American Indians, even those who are federally recognized, enrolled members of a tribe and are eligible for IHS services, cannot access the services once they leave the reservation. The problem is that all Indians do not live near the IHS facilities or on the reservation. Therefore, I see this policy as a major health disparity, which must be addressed if the health of American Indians is to be improved," concluded Richardson.

For more information on American Indian health care services, go to <http://www.ihs.gov>. ◆



*Indian Health Service Continues to Provide for Millions* is based on the Summit workshop "Where Do Native Americans Who Are Not Covered by IHS go for Healthcare?"

# Managed Care Moves to the Head of the CLAS

## *Implementing Culturally and Linguistically Appropriate Services*

Brigette Settles Scott, MA

As the U.S. population becomes more diverse, medical providers and other people involved in health care delivery must interact with patients from many different backgrounds. Culture and language are new vital factors in how health care services are delivered and received. Today, it is important that health care providers understand and respond with sensitivity to the needs and preferences that diverse patients bring to the health encounter. Providing culturally and linguistically appropriate services (CLAS) to these patients has the potential to improve access to and quality of care, and ultimately, health outcomes.

“The system by which health care is delivered and financed must be designed to ensure the care is safe, effective, efficient, equitable, and tailored to each individual’s specific needs and circumstances,” recommends the Institute of Medicine Report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, released early last year.

Once thought of as unrealistic goals or expectations, cultural competency programs and initiatives are now being implemented in managed care organizations and other health care settings across the country. The *National Standards for Culturally and Linguistically Appropriate Services in Health Care*, published by the Office of Minority Health (OMH) in late 2000, serves as a springboard for use by providers and others seeking to address cultural issues within their delivery systems.

According to Guadalupe Pacheco, public health advisor at OMH, policy makers, accreditation agencies, purchasers, patients, advocates, educators, and health care communities use CLAS as a vehicle to improve health. “Cultural competence is the ability of health organizations and practitioners to recognize the cultural beliefs, attitudes, and health practices of diverse populations, and to apply that knowledge in every intervention—at the systems level or at the individual level—to produce a positive health outcome,” said Pacheco.

“Major HMOs have undertaken CLAS as a vehicle to provide appropriate cultural and linguistic care to a diverse population,” added Pacheco. “This is the first time these organizations have seen clear pathways to culturally and linguistically appropriate services. Before, everyone was doing his or her own thing. With CLAS people can make improvements by building on these standards.”

### Implementing CLAS

In partnership with OMH, the American Institute for Research (AIR) developed curriculum modules for implementing CLAS. The four-year project launched in 2001 is working with family practitioners and plans to pilot test the modules in a variety of health care settings.

The CLAS pilot project will report on guidelines and processes for implementing standards in health care organizations, identify potential barriers, and measure impact on providers and patients.

“In an effort to provide culturally competent care to a multicultural, ethnically diverse population, the pilot project is a way to identify health disparities and deliver case management services, analyze members’ health status, educate members about preventive health and improve access to early screening, diagnosis, and treatment,” said Pacheco.

In 2002, Alameda Alliance for Health, a managed care health plan serving low-income populations throughout Alameda County in the city of Oakland and Northern California, was chosen by OMH as the first study site for the implementation of the CLAS standards in a managed care organization.

Through more than 1,300 public and private physicians, hospitals, and community clinics, the Alliance provides comprehensive medical and behavioral health services to more than 80,000 members—45 percent with a primary language other than English and 87 percent representing various racial and ethnic minority groups. With a racially and linguistically diverse workforce and membership, and cultural competency standards already in existence, the Alliance was an ideal study site.

Dr. Juanita M. Dimas, cultural and linguistic program manager, said the Alameda Alliance began in 1996 and has always been committed to the culture and health of the population it serves. “Originally chosen as a pilot site, Alameda Alliance is now more of a case study since there were a number of similar standards in place,” she said.

“The CLAS standards have been a help in guiding Alameda Alliance, but they are our minimum goal. Our systemic approach helps to avoid defining cultural competency as the final desired outcome, and instead, desired outcomes are defined as quality of care at the member/patient level, provider level, and MCO level,” concluded Dimas.

*For more information on the Alameda Alliance for Health, go to <http://www.alamedaalliance.com>* ♦

*For more information on the Office of Minority Health’s National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS), go to <http://www.omhrc.gov/clas>* ♦

*For more information on how to implement a cultural competency program in your organization, see page 18.* ♦

*Managed Care Moves to the Head of the CLAS  
is based on the Summit workshop  
“Cultural Competence of Health Care Organizations.”*

# Health Care is *Not* Color-Blind

## *Race Impacts Access to Care*

Kauthar B. Umar, MA

Within the past decade, experts have made great research investments to find out if health care was indeed color blind. And, many are not too pleased with the answer. Despite the fact that we are all the same on the inside, research shows that race partially determines who has access to health care and how much care is available.

According to Dr. Vanessa Gamble, health policy consultant, member of the National Advisory Council for Healthcare Research and Quality, and author of *Making A Place for Ourselves: The Black Hospital Movement, 1920-1945*, disparities need to be viewed in the context of how race has been viewed historically and how it has changed.

“Race is a powerful social construct that has an impact on health outcomes,” said Gamble. “We need to decide what it means. There was a time in this country when people, because of the color of their skin, were not allowed in hospitals. There was a segregated hospital movement and system in the country, and for a lot of elderly African Americans, they remember it and that influences their perception of our health care system,” Gamble added.

Socioeconomic status, health practices, psychosocial stress, resources, environmental exposures, and limited English proficiency are additional factors believed to contribute to racial and ethnic disparities in health care, which impact the unequal burden of disease and mortality among the diverse racial and ethnic populations.

Only by re-tracing what Gamble refers to as the “medical civil rights movement,” can a clear picture of today’s system be drawn. Acts were passed and followed by cases that challenged hospital segregation at Federal and privately-funded hospitals. From the civil rights legislation to anti-discrimination clauses in Medicare and Medicaid, the fight for equal health care has been an ongoing battle that Gamble stresses is still being fought.

“When people were trying to desegregate hospitals they were trying to get access to care, but they were defining access to care as simply being allowed to get into the door,” said Gamble. “What we have to talk about today in terms of the medical civil rights movement is what happens once you get in the door.”

According to Gamble, the medical civil rights movement, originally based on a Black/White dichotomy, has changed drastically, but still continues. “Language proficiency found its way into the picture, as the U.S. became more diverse. With the ever-changing face of the nation there are still remnants of segregation in this country. This segregation appears to be color neutral, but in actuality, it is history repeating itself,” she added.

*Health Care is Not Color-Blind* is based on the Summit workshop “Race and Access to Health Care.”

### Affecting Today’s Community

The history of race in the U.S. and how it affects access to health care today, has been linked with a lack of financial resources as one of the many barriers to equal health care for people of color. Released in 2002, the Commonwealth Fund’s 2001 Health Care Quality Survey found that Hispanics and African Americans are most at risk of being uninsured. Minorities in general have lower rates of insurance coverage and as a result, less access to health care.

Despite insurance status, the survey’s findings indicate that minorities are more likely than Whites to be disconnected from their regular sources of care and the health care system overall. Uninsured minorities are more likely than uninsured Whites to experience difficulties in accessing health care. During the year prior to the survey, those who were temporarily or permanently uninsured—39 percent of Hispanics, 38 percent of African Americans, and 32 percent of Asian Americans—said they had very little or no choice in their source of health care. On the other hand, 25 percent of uninsured Whites reported very little or no choice in source of care.

“Minorities are facing different barriers today,” said Dr. Jose Arbelaez, a data analyst at Johns Hopkins School of Medicine. “One of the most important [barriers] is the lack of health insurance, a big factor among African Americans and other minorities.”

Arbelaez said that rates of the uninsured and underinsured, particularly among African Americans, remain very high, affecting how care is received. A 1998-99 Allegheny County Health Department project, in collaboration with Johns Hopkins School of Medicine, explored demographics, barriers to health care, interaction with providers, and medical myths in a cross-sectional study of more than 200 community members in the Pennsylvania county.

The study found that 28.6 percent of African Americans and 13.5 percent of Whites had difficulty receiving care in the previous 12 months. African Americans were five times more likely to be asked their availability to pay for treatment, independent of their insurance status. Twenty-five percent of African Americans and 45.3 percent of Whites reported that providers made payment allowances for them, while 38.2 percent of African Americans and 22.1 percent of Whites were referred to collection agencies for medical bills.

Statistics and research show that the health care experience for Whites and people of color differ dramatically throughout the nation. According to Arbelaez, health care barriers, such as financial need, low literacy, and discrimination provide an answer to the question, is health care a color-blind process? To many, unfortunately, the answer is no.

To contact Dr. Vanessa N. Gamble, call 202-299-0430. ♦

For more information on the 1998-99 Allegheny County Health Department project, contact Dr. Jose Arbelaez, at 410-955-6953 or jarbelae@jhsp.edu ♦

## The Jackson Heart Study *Benefiting the Community*

Through community awareness, health education programs, and academic opportunities, the Jackson Heart Study aims to:

- ❖ Enhance the community's health awareness and understanding of cardiovascular disease through seminars and workshops on cardiovascular disease, diabetes, hypertension, cholesterol, and nutrition;
- ❖ Provide insight into the development of new treatments for cardiovascular disease in African Americans;
- ❖ Assist medical professionals in their understanding, diagnosis, and treatment of cardiovascular disease in African Americans;
- ❖ Identify risk factors for cardiovascular disease in African Americans;
- ❖ Enhance research capabilities at minority institutions by developing partnerships;
- ❖ Provide an opportunity for African Americans to provide meaningful input into the development of a major research project that impacts their health;
- ❖ Provide an opportunity for African Americans to leave a legacy of health for their future generations; and
- ❖ Provide academic opportunities for minority high school students, college students, and health professionals in the health sciences.

## Strengthening the Community *Academic Partnerships for Research*

Aimee Swartz

By partnering with locally-based organizations, universities have the means and the mission to transform their communities into safer, more productive, and healthier places. The Jackson Heart Study (JHS) in Jackson, Mississippi is one such effort. JHS is an epidemiological investigation of cardiovascular disease (CVD) among African American men and women in the Jackson metropolitan area. It is a partnership among two, local Historically Black Colleges and Universities—Jackson State University and Tougaloo College—the University of Mississippi Medical Center, the National Institutes of Health's Center for Minority Health and Health Disparities, and the National Heart Lung and Blood Institute.

“Cardiovascular mortality rates in Mississippi are the highest in the U.S. and are almost 25 percent higher than the national average,” said Cynthia Smith of the Jackson State University Medical Center.

Heart disease and stroke are the first and third killers of all Americans, with a disproportionate burden carried by African Americans. CVD is known to be higher in African Americans than all other racial and ethnic groups, but reasons for these differences have yet to be determined.

JHS studies the factors that influence the development of CVD in African American men and women. Emerging factors include genetics, racial discrimination, and socioeconomic status.

An offshoot of the Atherosclerosis Risk in Communities study, the JHS is a three-year project that began in the fall of 2000. By the end of study enrollment, there will be 6,500 African American men and women, ages 35-84, rendering it the largest CVD study conducted to date in the African American population.

“The church is the cornerstone of the African American community,” said Smith, who does outreach at local churches, spreading the word of the JHS, as well as general cardiovascular health. “The JHS was built on the premise that the community is best able to solve local problems.”

In an effort to establish an environment of trust in and support of JHS, Smith and her colleagues work to ensure that local community members are

involved in every phase of the study. “We also conduct health promotion and education activities that stress the importance of healthy living, CVD disease, and other health topics,” Smith said.

“Participation in the JHS does not only identify risk factors and treatment options for CVD in African Americans, but it also provides an excellent opportunity for African Americans to leave a legacy of health for future generations,” she said. “It’s about doing ‘with’ and not doing ‘to’ the community,” she added.

*For more information about the Jackson Heart Study, call 601-368-4650 or go to <http://www.jsums.edu/~jhs>* ♦

### Minority Cardiovascular Disease Deaths in 2000

77,523  
African Americans

25,819  
Hispanics

9,101  
Asians/Pacific Islanders

2,417  
American Indians/Alaska Natives

Source: *Health, US, 2002*

*Strengthening the Community—Academic Partnerships for Research* is based on the Summit workshop of the same title.

ASPIRA, which comes from the Spanish word *aspirar*, meaning to aspire, was founded in 1961 in New York City. According to Crespo, parents and the community collaborated efforts to address the high school drop out rate of Latino students in NYC, which was nearly 70 percent at the time.

“The community felt that something had to be done, because the social and economic development of the Latino community depended on future leaders, and the youth were our future,” said Crespo.

Today with offices in seven states, ASPIRA’s 3,000 staff members and volunteers work with approximately 40,000 youth each year. Each state has an office with multiple centers. Crespo said ASPIRA developed agreements with public school systems to have staff members work in schools promoting empowerment for the Latino youth.

Programs like ASPIRA’s Math and Science Academy work to improve the math and science skills of Latino middle school students by incorporating hands-on activities, mentors, field trips, and academic assistance. Through its Youth Leadership and Community Service initiative, youth are able to take part in programs that expose them to a variety of professions, including medicine and the health sciences.

“In an era when Hispanics have a drop-out rate of 55 percent, ASPIRA participants have high school graduation rates of 98 percent,” said Crespo. “Approximately 84 percent of our graduates go on to attend college. These kids are from urban areas and are the first to attend college in their families,” she added.

ASPIRA believes that by working with youth and developing them socially and academically, it is fostering the doctors and lawyers of tomorrow. “We introduce youth to health-related fields by providing workshops and mentors from the health field. By improving the educational experiences of youth and exposing them early on in their academic career to math and science and the health professions, we believe we will have more kids choosing to work in health care,” she concluded.

For more information on ASPIRA, go to <http://www.aspira.org> or call 202-835-3600. ♦

*Start 'Em Early, Start 'Em Young Introducing Minority Youth To Health Professions* is based on the Summit workshop “Lost Opportunities: The Difficult Journey to Higher Education for Minority Medical Students.”

## Resources

### Cultural Competence

Need more information on how to implement a cultural competency program in your organization? Consider the following resources on the Internet:

- ❖ *National Standards for Culturally and Linguistically Appropriate Services in Health Care*  
Go to <http://www.omhrc.gov/omh/programs/2pgprograms/finalreport.pdf>
- ❖ *Teaching Cultural Competence in Health Care: A Review of Current Concepts, Policies and Practices*  
Go to <http://www.air.org/cccm/practices/scanfinal.pdf>
- ❖ *Let Everyone Participate—Access for People with Limited English Proficiency*  
Go to <http://www.lep.gov>
- ❖ *Cultural Competence Works: Using Cultural Competence to Improve the Quality of Health Care for Diverse Populations and Add Value to Managed Care Arrangements*  
Go to <http://www.hrsa.gov/financeMC/ftp/cultural-competence.pdf>

### Educational Resources

For more than 30 years, the National Institute of General Medical Sciences (NIGMS), a component of the National Institutes of Health (NIH), has administered the Minority Access to Research Careers (MARC) and Minority Biomedical Research Support (MBRS) programs. As just two of the many NIH initiatives for minorities, these programs provide a solid foundation for success, by supporting research and research training that are designed to increase the number of minority biomedical scientists. In addition to providing funds for education and research infrastructure improvements in U.S. institutions, the programs provide participants with training opportunities, laboratory equipment, supplies, and mentors.

For more information on the MARC program, contact Dr. Adolphus Toliver at 301-594-3900 or go to <http://www.nigms.nih.gov/minority/marc.html> ♦

For more information on the MBRS program, contact Dr. Hinda Zlotnik at 301-594-3900 or go to <http://www.nigms.nih.gov/minority/mbrs.html> ♦

### Organ Donor Resources

#### African Americans Uniting for Life

<http://webusers.xula.edu/jeckert/hoa/aaul.html>

#### Asian Pacific Islander Donors Can Save Lives

[http://www.marlow.org/NMDP/api\\_english.html](http://www.marlow.org/NMDP/api_english.html)

#### Association of Organ Procurement Organizations

<http://www.aopo.org>

#### Hispanics Giving Hope

[http://www.marlow.org/NMDP/hgh\\_english.html](http://www.marlow.org/NMDP/hgh_english.html)

## Resources

### LifeCenter Northwest Donor Network

<http://www.lcnw.org/index.cfm>

### Life Net

<http://www.lifenet.org/>

### Keep the Circle Strong

<http://www.marow.org/NMDP/aian.html>

### National Marrow Donor Program

<http://www.marow.org>

### National Minority Organ and Tissue Transplant Education Program (MOTTEP)

<http://www.nationalmottep.org>

### Organ and Tissue Donation/Transplantation

<http://www.organdonor.gov>

### Touchdown for Life

<http://www.themarowfoundation.org/DnrRecruit.htm>

### United Network for Organ Sharing

<http://www.unos.org>

## Organizations

### Alameda Alliance for Health

1240 South Loop Road  
Alameda, CA 94502  
510-747-4500  
<http://www.alamedaalliance.com>

### The ASPIRA Association

National Office  
1444 Eye Street, NW  
Suite 800  
Washington, DC 20005  
202-835-3600  
<http://www.aspira.org>

### District of Columbia Department of Health

825 North Capitol Street, NE  
Washington, DC 20002  
202-442-5999  
<http://dchealth.dc.gov/index.asp>

### FACED—Faith Access to Community Economic Development

310 E. Third Street, 5th Floor  
Flint, MI 48503  
810-232-7733  
<http://www.sph.umich.edu/prc/projects/reach.html>

### National Medical Association

1012 Tenth Street, NW  
Washington, DC 20001  
202-347-1895  
<http://www.nmanet.org>

opened at Howard University Hospital. Today there are 15 additional sites throughout the U.S. and its territories. The efforts of MOTTEP have expanded to other minority communities including, Hispanics/Latinos, American Indians/Alaska Natives, and Asian Americans/Pacific Islanders.

As the first program of its kind in the U.S., MOTTEP is designed to educate minority communities on facts about organ and tissue transplantation. It empowers minority communities to develop transplant education programs that allow them to become involved in addressing the shortage of donors. MOTTEP increases minority participation by encouraging and increasing family discussions related to organ and tissue donation.

MOTTEP's mission recently expanded to include a prevention message. It created a new theme to reflect the change, "Love Yourself, Take Care of Yourself." This message is meant to encourage individuals to adopt healthy behaviors, including eating balanced, nutritious meals, exercising, and avoiding unhealthy behaviors such as eating a diet high in fat and cholesterol, being overweight, and abusing drugs and alcohol—behaviors that could lead to the need for a transplant.

### A Look to the Future

Along with the *Gifts of Life* Donation Initiative, Secretary Thompson also unveiled a model organ and tissue donor card that incorporates proven elements from existing donor cards. He also commissioned a national medal to honor donors and their families at national and regional ceremonies.

"Dying from needing an organ is preventable," said Paul Schwab, executive director, Association of the Organ Procurement Organizations.

"The opportunity to save the life of a stranger is a heroic act. Sometimes it takes more of a personal sacrifice to get the job done," added Secretary Thompson.

*For more information on organ and marrow donation and Federal initiatives, go to <http://www.organdonor.gov>* ♦

*For more information on the National Marrow Donor Program, go to <http://www.nmdp.org>* ♦

*You Too Can Save a Life* is based on the Summit workshop "Organ Donation and Marrow Donation Program—Now More Than Ever"

## DEPARTMENT OF HEALTH & HUMAN SERVICES

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Office of Minority Health Resource Center  
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Washington DC 20013-7337

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## Conferences

### August 27-29, 2003

#### 8th Annual Minority Health Summit

*Our Health Is In Our Hands*

Sheraton Music City Hotel, Nashville, TN

Contact: Tennessee Office of Minority Health

615-741-9443

<http://www2.state.tn.us/health/minorityhealth/2003%20Summit.pdf>

### September 18-21, 2003

#### U.S. Conference on AIDS

*Paving the Way for New Directions*

Hyatt Regency at the Superdome, New Orleans, LA

Contact: National Minority AIDS Council

202-483-6622

<http://www.nmac.org>

### September 22-23, 2003

#### Hispanic Heritage Month 2003 Issues Conference

4 Points Sheraton, Washington, DC

Contact: Congressional Hispanic Caucus Institute

202-543-1771

<http://www.chci.org>

### September 25-28, 2003

#### United States Hispanic Leadership Institute 21st Annual Conference

*Latino Leadership: Making Democracy Work*

Hyatt Regency, Chicago, IL

Contact: United States Hispanic Leadership Institute

312-427-8683

<http://www.uskli.com>

### September 29 - October 2, 2003

#### National Indian Health Board Annual Consumer Conference

*Maximizing Resources through Partnerships: The Future of American*

*Indian & Alaska Native Health Care*

Radisson Riverfront, St. Paul, MN

Contact: National Indian Health Board

202-742-4262

E-mail: [acc03@nihb.org](mailto:acc03@nihb.org)

<http://www.nihb.org>

