



Increasingly Urban AI/AN Population Faces Poverty, Barriers To Health Care

By Matt Pueschel

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WASHINGTON—A new report released in November by the Urban Indian Health Commission and funded by the Robert Wood Johnson Foundation illuminated concerns over rising health disparities in American Indians and Alaska Natives (AI/AN) living in urban areas.

Entitled "Invisible Tribes: Urban Indians and Their Health in A Changing World," the report details how nearly 67 per cent of the country's 4.1 million self-identified AI/AN now live in metropolitan areas and how many are poor with high rates of chronic ailments but lack the means to access health care. There are only 34 urban Indian health organizations (UIHOs) across the country, but they receive only 1 per cent of the Indian Health Service (IHS) budget. In FY '06, IHS provided about \$32.74 million that went toward serving about 100,000 Indian people in the urban programs. In FY '07, about \$33.691 million from IHS went to serve about 175,000 patients in the programs.

Over the last 30 years, more than one million AI/AN have left reservations and moved to cities in search of better opportunities. "This change in lifestyle has left many in dire circumstances and poor health," the report said. "American health care and America's leaders largely ignore these people. A large proportion of urban Indians is living in or near poverty and thus faces multiple barriers to obtaining care. Without informed dialogue and targeted action, the health of urban Indians will continue to decline."

Even the austere IHS funding for the urban programs was proposed to be eliminated by the Bush administration in both FY '07 and FY '08. But Congress stepped in and put the money back in the budget both times. The Bush administration has again proposed eliminating it in FY '09. "There is no national, uniform policy regarding urban Indian health, and current federal executive policy aims to eliminate funding for urban Indian health within the Indian Health Service," the report said. "Legislation enacted and treaties signed during the last century guaranteed health care for American Indians and Alaska natives, but for the most part, recent policies have stripped many of them of their rights to health care when they move to cities. With only one per cent of the Indian health budget allocated to urban programs and with this one per cent under threat of elimination, these Indian-operated clinics must struggle to obtain and maintain the funding, resources and infrastructure needed to serve the growing urban Indian population."

The Urban Indian Health Commission, an 11-member board created to address disparities in

Indians, convened a conference on Nov. 1 in Washington, D.C., to discuss the report and raise awareness of its findings. Ralph Forquera, MPH, executive director of the Seattle Indian Health Board (home of the commission and also one of the 34 AI/AN urban health care facilities across the country), said the report is a result of two years of work. He said there is still limited information on urban Indians, but it is clear they are suffering from health disparities.

"This is a segment of our population that many people don't understand very well, and America's leaders ignore these people," said Michael Painter, senior program officer at the Robert Wood Johnson Foundation. He said that outpatient and provider organizations, hospitals and officials can use the information in the report to determine what is needed to address these disparities, and consumers can use it to advocate for improved health care that is specific to their needs. He called the report a "wake-up call."

Painter cited an example of a severely diabetic Indian woman in her 50s who was living in an urban area and was noncompliant with her medications. "She was afraid of meds because she was homeless and had limited access to meals," he said. "But she made strides in an urban Indian clinic, and six months later [she improved significantly]."

Asked to comment on the report, Phyllis S. Wolfe, Director of Urban Indian Health Programs for IHS, said in a phone interview that "it clearly documents the situation as things exist today. That's just an excellent report."

When asked why the Bush administration proposed eliminating IHS funding for urban Indian programs, Wolfe said she had no comment on that. "The report is a very fine report, and it accurately documents the state of urban health," she said.

Cindy Darcy, majority staff director of the Senate Indian Affairs committee, said the Interior, Environment and Related Agencies appropriations subcommittee put the urban care funding back in the FY '08 budget. "We recommended strongly that that program be restored," Darcy said. "The interior appropriations committee actually put the money back in. Both the House and Senate restored the urban program."

The urban Indian funding was set at \$35.1 million (an increase over last year's amount of \$33.691 million) and the overall IHS budget was approved at \$3.39 billion (which was more than the administration's \$3.27 billion FY '08 request and the \$3.18 billion FY '07 enacted level). However, both amounts were later subjected to a 1.56 per cent across the board cut before Congress passed the final version of an omnibus appropriations bill for FY '08 that was signed into law in late December. The actual FY '08 account for the IHS urban Indian health program is now \$34.55 million, and the overall IHS total is \$3.346 billion. The administration has actually proposed a slight cut in FY '09, at \$3.325 billion, and has again proposed eliminating the urban health program, zeroing it out in its FY '09 budget proposal.

The Senate is also considering reauthorization of the Indian Health Care Improvement Act, which Darcy said would add some new Title V (health program) authorizations and services

for IHS and tribal programs.

On the Web site for the Senate Indian Affairs committee, Sen. Byron Dorgan (D., N.D.) stated that the Indian Health Care Improvement Act would renew and improve a broad range of Indian health programs by directing resources to combat the chronic shortage of health care services in American Indian communities. The legislation would authorize additional tools for tribal communities to address suicide among Indian youth; seek to address the lack of access to health care services, due to limited hours of operation of existing facilities, by establishing grants for demonstration projects that include a convenient care services program as an alternative means of health care delivery; address a \$1 billion backlog in needed health care facilities, such as alcohol and substance abuse treatment centers, and a \$1 billion unmet need for sanitation facilities in tribal communities; make permanent several successful federal programs that provide services to Native Americans in long-term health care, diabetes prevention and other areas; and expand scholarship and loan programs that encourage more American Indian people to enter health care professions.

If reauthorized, the act would then depend on the appropriations process for FY '09 to actually get funding for the programs. The act was debated in the Senate in late January, but no decision was reached. Darcy said the committee hopes to get it done soon. She also said that there is a possibility that someone will bring an amendment to the reauthorization bill to try to eliminate the urban Indian program, but added that it is hoped there would be enough support to defeat it. No such amendment was brought forward in the initial debate on the bill, but action on the bill is still pending.

Report Findings

The urban Indian report focused on depression, diabetes and cardiovascular disease, stating that they deserve special attention due to their alarming presence in the AI/AN population. "Our commission focused on three diseases, which frequently co-exist and have a serious and deadly effect on our people," said Dr. Theresa Maresca, director of the Native American Center of Excellence at the University of Washington.

Compounding things, Dr. Maresca said, is that there are few Native American doctors, and low cultural competency levels and lack of training among other primary care providers.

Depression:

The report said that some studies have shown up to 30 per cent of all AI/AN adults suffering from depression, and the proportion may be even greater among those living in cities. It also said that more than a third of IHS patient care contacts in 2006 were related to mental health, alcoholism or substance abuse. "Few urban Indian health organizations have sufficient funding to create useful and sustainable mental health programs," the report said. "With few American Indian or Alaska Native health professionals, and with many primary caregivers lacking sufficient mental health training, urban Indians are not, in most cases, receiving adequate mental health care."

Diabetes:

The report showed that between 1990 and 1999 the diabetes death rate was 32 per 100,000

AI/AN living in counties served by urban Indian health organizations—a rate significantly higher than that of the general urban population. According to the Centers for Disease Control and Prevention, in 2005 about 15 per cent of AI/AN ages 20 or older who receive care from IHS had type 2 diabetes, which exceeds the 9.6 per cent national rate in the general population.

The report detailed some of the positive impacts that urban Indian facilities can have. The South Dakota Urban Indian Health, Inc., for example, provides bikes to kids so they can ride to school for exercise. It is part of the IHS Special Diabetes Program for Indians started in 1997 to increase school physical activity, wellness and nutrition programs, as well as diabetes prevention and treatment services and data collection. "Urban Indian health organizations are a part of this initiative and have been successful in reaching urban Indians," the report said. "This initiative proves the value of targeted interventions and the ability of community-based organizations to better serve hard-to-reach populations like urban American Indians and Alaska Natives."

Cardiovascular Disease:

The report said that studies show cardiovascular (CV) disease continuing to rise among American Indians, with new cases of coronary heart disease nearly twice that of the general population. CV disease is the leading cause of death among AI/AN, and up to 25 per cent of American Indian men ages 45-74 have signs of heart disease. Furthermore, diabetes raises the risk of stroke, and the AI/AN stroke-related death rate due to diabetes is more than triple that of the general population. Furthermore, obesity, physical inactivity and high blood pressure—all risk factors for cardiovascular disease—are growing problems among AI/AN youth.

"Studies show that coronary heart disease, high blood pressure and stroke are disproportionately prevalent among American Indians and Alaska Natives," the report said. "Often, heart disease accompanies diabetes, making treatment even more complicated and expensive. For urban Indians, access to both diagnostic tests and specialized cardiac care cannot be assured due to poverty, lack of insurance and the limitations of urban Indian health organization services. The current UIHO network is an incomplete system offering only preventative and primary health care, which limits the ability of urban Indians to receive adequate and timely treatment of cardiovascular problems."

Jeffrey Henderson, MD, MPH, a Cheyenne River Sioux and president and CEO for the Black Hills Center for American Indian Health in Rapid City, S. D., said if an American Indian lives on a reservation, he or she could go to IHS for CV care and likely be contracted out for specialized care with IHS funds. However, for urban Indians who live near and utilize one of the 34 UIHO clinics, they cannot guarantee payment and referral for specialty services. "Urban Indian males under 45 are twice as likely to have CV risks, [and AI/AN women are one and a half times greater to have it than non-Hispanic white women]," Dr. Henderson advised. "Alcohol abuse and dependence are significant and serious issues among our people, also. But we also have the greatest number of non-drinkers, surprisingly. Commercial tobacco use also is a concern. [But] depression, diabetes and cardiovascular disease are very

prominent and addressable."

Path To Visibility

Martin Waukazoo, CEO of the Native American Health Center in Oakland, also spoke at the Nov. 1 conference. Before his presentation, he led the room in a spiritual chant, intermingling words in English and his native Rosebud Sioux about coming together to make positive change. "For too long, urban Indians have been invisible, while their health has declined," he said afterward.

Waukazoo said there is an increasing and emerging AI/AN elderly population, as well as a growing young population. "But resources are not coming in to address this," he advised. "We are becoming less invisible, and it is very important that this report is shared. I'm proud of our community. We've held onto our culture, traditions, dance, trying to move forward in a good way, and we're proud and strong and determined to improve our health."

Michael Bird, MPH, MSW, former president of the American Public Health Association, said public efforts must assist and recognize Indians living in cities. "We must expand the number of Native American health professionals," he said. "We need to ensure the provision of technical assistance. We need to support urban Indian programs through IHS. The bottom line is if you do not include us, you exclude us."

The Urban Indian Health Commission offered several recommendations in the report: that efforts to improve care quality and reduce disparities must assist and recognize Indians living in cities; to expand IT capacity of UIHOs to improve care and data collection, and utilize best practices and initiatives like the Special Diabetes Program for Indians for other conditions such as CV disease and depression; ensure urban AI/AN are included in all data collection efforts to improve care quality such as regional improvement collaboratives; expand the number of Native health professionals by working with local colleges and other institutions, and support the integration of traditional medicine in health care delivery; provide technical assistance to build partnerships with local health providers and improve access to insurance; support the urban programs through IHS; include AI/AN in national programs dealing with health disparities and minority health initiatives; and encourage public and private partnerships that help urban Indians' health access.

Funding Issue

In both FY 2007 and 2008, Forquera said the Bush administration's budget proposals zeroed out IHS funding for the urban Indian health programs. Forquera and the National Council of Urban Indian Health asked for an increase to \$40 million this year, which is several million more than what Congress reinstated it at. "The need is far greater, but we tend to be realist when it comes to Congressional appropriations for Indian issues," he said. "The IHS overall and the BIA (Bureau of Indian Affairs) are both grossly underfunded. Being a part of the domestic discretionary budget and in (the Department of the) Interior, the smallest agency budget, is a further hinderance."

Furthermore, specialized care is often rationed throughout IHS, in general, due to a lack of funding. "No Indian anywhere has comprehensive health care through IHS," said Linda

Burhansstipanov, DrPh, MSPH, grants director for the Native American Cancer Research, at the Nov. 1 meeting. "It is incredibly underfunded. It is a myth that Indians have comprehensive health care under IHS."

The other concern is the administration's repeated attempts to strip out the urban program funding. "This is simply not right," said Burhansstipanov. "Urban Indians are so disenfranchised. It is absolutely unconscionable and criminal that the administration continues to try to take away money from the urban Indian health programs. Not only that, but they try to shift money away from the Department of Health and Human Services. All of our urban Indian programs are underfunded. Only 1 per cent of the IHS budget is going to 60-70 per cent of our community. A big way to address our disparity is through strong support of urban Indian health programs."

Rep. Frank Pallone, Jr., (D., N.J.), chairman of the House energy and commerce subcommittee on health and vice chair of the Congressional Native American Caucus, said in a statement that the commission's report further emphasizes the need for a greater focus on the health care needs of Native Americans. "Urban Indian health programs need more funding and more flexibility in order to expand their reach and truly serve a needy urban Indian population," he said in a statement. "As it stands, Indians in our cities and on tribal lands have too few resources to respond to the epidemics of diabetes, heart disease and obesity from which they suffer disproportionately."

Rep. Pallone and five other members of the caucus also signed an Oct. 30 statement urging attention to the issue. "While the United States Congress has an obligation to provide health services to Indians on Indian reservations, it is important that we do not lose sight of the fact that many Indians live in cities, as well," the statement said. "Congress must provide needed funding, but it is important that state and local governments, as well as the private sector, chip in."

Forquera told U.S. MEDICINE that Congress has not been the problem. "It has been the Bush Administration," he said. "The Bush folks have eliminated urban funding from the President's budget each of the past two years. The Congress has put it back with bipartisan support. So our beef is not with Congress, it is with the Administration."

As a matter of comparison for the people who were served by the urban programs, IHS' approximate \$33 million to serve about 100,000 patients adds up to only \$330 per person annually, Forquera said, adding that Medicare pays about \$6,000 per person [the Congressional Budget Office's baseline projections of Medicare benefits per enrollee was actually \$6,512 in 2002]. "Urban Indian health is also an incomplete program," Forquera said. "We are doing primary care at the best urban facilities, not specialty care, and we are not able to guarantee that [specialty] care for patients we see."

Painter said the point of the report is to raise awareness to put urban Indians front and center. "The facts tell us that we are not important to our government and that has an effect on our people and our morale, and that's when the elders step forward and help us," Forquera said.

The report can be viewed on the Web site of the Robert Wood Johnson Foundation, at <http://www.rwjf.org/newsroom/newsreleasesdetail.jsp?productid=23192&typeid=160>.

IHS Response

Wolfe declined to comment on why IHS and the administration continually attempt to cut federal funding for the urban Indian health programs, but she said that in fiscal year 2007, the Department of Health and Human Services (HHS) conducted tribal consultation, and the department clearly heard the tribes' priorities. "One of their top priorities for funding in the department was indeed the urban Indian health program," she said.

However, the administration's subsequently proposed FY '08 budget had zero money in it for the urban Indian health program. An alternative to the urban Indian programs that has been touted by some federal officials is the HHS Bureau of Primary Health Care within the Health Resources and Services Administration (HRSA). It funds community health centers that are open to the general public. However, Wolfe acknowledged that if urban Indian health care funding from IHS was eliminated, HRSA's community health centers, even with increased funding, would not be able to substitute for it. "The funding that has been made available, the additional resources received by that agency have been designated specifically for developing and implementing community health centers in rural areas," she advised. "[But quite frankly,] HRSA's Bureau of Primary Health Care [has] confirmed that they are not able to absorb the urban Indian population."

Furthermore, the report said that although some poor and near-poor urban Indians in cities without urban Indian health organizations rely on the HRSA-funded community health centers for care, these centers are under increasing strain as growing numbers of middle-class Americans who have lost their employer-sponsored insurance turn to them for help. "In addition, these centers do not always provide culturally appropriate services for urban Indians," the report said. "These same concerns apply to urban Indians' use of hospital emergency rooms for primary care services."

When asked if IHS funding for the urban programs is eliminated, what would happen to the 34 urban Indian health programs, Wolfe was candid. "Several of them would go out of business," she said. "The IHS provides core funding for these programs and they are very effective at leveraging the small amount of resources that they do receive from Indian Health Service. You would not see the urban Indian health program at the level it exists today if those resources went away from IHS."

Wolfe told U.S. MEDICINE that the 34 urban Indian health programs provide quality health care and culturally competent care for AI/AN that reside in those cities. "Those people served by urban Indian health programs are people that, were those programs not available to them, they would wait until they are so sick that they have to present themselves at the emergency room of their local hospital," she said. "That is not a good situation."

Value Of Urban Programs High

Wolfe said the urban Indian programs focus on health promotion and disease prevention. "The prevention and education that is provided in these urban programs is simply

outstanding," she said. "The focus on diabetes prevention education has made a significant difference in the people who obtain their health care at the urban Indian health programs. The focus on mental health, alcohol and substance abuse prevention and treatment programs with the small level of funding that they have...they have outstanding health promotion disease prevention programs. Wellness, nutrition, diet, exercise—those are all important pieces of the health program that is provided."

Wolfe cited an example of an elderly woman who was in danger of losing a leg to diabetes before she went to the urban Indian program in Omaha, Nebraska. "The people at the urban Indian health program and the diabetes program said, 'Well, we can't guarantee that you won't lose a limb, but we will work with you to see what we can do to help in this situation,'" Wolfe said. "I got to meet this woman and she took off her right shoe and she was so happy. She said, 'Look here, they did amputate my toe, but I've got four toes, my foot and my leg and I feel whole as a result of that.' She lived two good, sound, solid years following that removal of just one toe, and she made sure that her grandchildren who were diabetic (they had problems with their toes, too), she had them at the urban clinic receiving preventative health care for diabetes."

Wolfe also said that the 34 urban programs are required to survey their area populations and determine what their needs are. "Urban Indian programs make a difference in people's lives and they do provide quality health care services," Wolfe advised. "There is a large population that [is] dependent on the urban Indian health programs for their health care in the urban cities, and they leverage a very small amount of IHS resources that enable them to provide significant health care for urban American Indians and Alaska Natives."

Burhansstipanov added that half of AI/AN women are diagnosed with breast cancer before the age of 50. She said nurses work with them to ensure they utilize spiritual medicine and dance. "So, we combine with western medicine well in urban communities," she said.

The commissioners noted at the Nov. 1 meeting that the urban programs have done a remarkable job with limited funds. "We can engage individuals at the community level, and an example is the Special Diabetes Program," Forquera said. "So, you can engage people in their own health and you can move people from crisis situations to preventive mode. So, we have the ability to do that, unlike some other organizations."

Limitations

Wolfe said 21 of the 34 urban programs are considered "comprehensive" ambulatory facilities, but the range of services varies greatly among these programs. "Those are facilities that provide direct medical care to the population for 40 hours or more a week," she advised. "They have a medical provider on staff." While some of these programs can have two or more full-time doctors, as well as pharmacy, lab, radiology and dental services, others may have just one medical provider and no dental, pharmacy, lab or radiology. "The designation of 'comprehensive' is actually a relative term for a program which is not currently designed to be a truly comprehensive health program in the more commonly used sense of the word," according to IHS.

The other 13 programs are either part-time outpatient facilities, or outreach and referral sites.

Even the most comprehensive urban programs provide only primary health care and do not pay for specialty or referral care. The programs are neither IHS or tribally run, but are nonprofit organizations with a board of directors that is composed of at least 51 per cent AI/AN. "Those organizations give preference to hiring American Indians and Alaska Natives," Wolfe said. "They seek out AI/AN health care providers, medical doctors, nurses, the alcohol and substance abuse counselors, the mental health providers."

Wolfe said that no urban Indian health program has turned away an American Indian or Alaska Native or people who meet the eligibility requirements, including self-identified Indians. "They have not been turned away for health care services," she said. "We do accept self-identification as supporting documentation for being eligible. Some (urban) programs use a sliding fee scale and that is certainly fine, but other programs do not charge for the health care services that are provided."

One issue that sometimes arises is that sometimes AI/AN clients are resistant to providing information to the urban facility so that they can bill third party insurers. Wolfe said that the biggest reason for that is distrust of the government.

Furthermore, although the UIHOs have a focus on urban Indians, they must also serve anyone that seeks assistance. "Unlike tribal or IHS clinics, UIHOs are not exempt from federal or state non-discrimination rules," Forquera told U.S. MEDICINE in a follow-up email. "Thus, to keep our funding and non-profit status, we are required to serve anyone seeking assistance. The IHS does not seem to [always] understand this. Care is also not free. Clinical care is provided on a sliding-fee based on income and family size, like community health centers. This is often a requirement of both local and state grants for the uninsured that funds the bulk of our direct care efforts."

Cardiovascular disease is especially difficult to treat in the urban programs, given that they do not have specialty programs. "Yes, it is extremely difficult," Wolfe acknowledged. "They can focus on the health promotion, like tobacco (cessation), exercise, diet, nutrition, but when it's extremely complicated, if the person is extremely sick and the program is not able to handle it, then all they can do is refer the patient to another facility. And then it's whatever that facility can do to help them, based upon whatever resources they have available."

The urban programs' focus is prevention. "Urban programs do an outstanding job of focusing on health promotion and disease prevention, and behavioral health to reduce the risk factors of health conditions, such as HIV/AIDS, alcohol and substance abuse," Wolfe said. "Urban programs all have emergency preparedness plans. They have worked with their city, county and local facilities. They've done planning and preparation for pandemic flu, and certainly the personalized health care. Medical care, including traditional medicine, and prevention is provided by urban programs and enables our urban programs to target their clients and their health care system to give their patients and providers the means to make informed, personalized, effective health care choices."

Wolfe also said that the urban program in Milwaukee, Wisc., was selected to participate in IHS's chronic care collaborative to demonstrate that changing the way health care is delivered can improve patient outcomes. Furthermore, all of the urban programs participate in quarterly IHS chronic care collaborative conference calls to learn about best practices and how care is inter-related. "There is the depression and alcoholism, behavioral health, all of those elements filter in to the result that creates so many problems," Wolfe said.

More Urban Programs Needed

Another issue is that there are many areas in the U.S. with urban Indians that do not have a UIHO. "Only 34 communities get one per cent of the entire IHS budget, but we live in every city," Burhansstipanov advised. "[Some] people don't have access to pain medications, such as OxyContin. It is wrong to be tied to a bed in pain as a first nation member."

With 67 per cent of 4.1 million AI/AN across the country living in urban areas—some 2.5 million—the need for care well exceeds that of the mere 175,000 patients served by existing UIHOs last year.

In fact, a 1989 evaluation by the American Indian Health Care Association of potential site locations for new urban Indian health care programs came up with a list of 18 cities with no facilities that are more than 30 miles away from existing IHS or tribal Indian health clinics. The 18 sites have large numbers of Indians living below the 200 per cent poverty level, and with high mortality rates.

"The Indian population is big enough that we need to establish an urban Indian health program [in those other areas], but we don't have the resources to do it," Wolfe said. "Today, if we had the funding, there is a need in Orange County, Calif., [for example, and] there is a huge need in Grand Rapids, Mich., today for an urban Indian health clinic, but we simply don't have the resources to do it. So, when we tell you the number of people that we are serving, it's very small in relation to what the real need is. More of these would help in different places to reach more people."

Wolfe, whose staff includes just a health systems specialist and an administrative assistant, said, the IHS urban program office "is a bare bones operation, but we've done our very best to ensure that as much of the money as is absolutely possible can be put into the programs for health care services."

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