

# *Report*

*Native American*

*Community Consultation:*

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Access to HIV/AIDS Care Issues

February 3, 2004

Doubletree Hotel and Executive Meeting Center

1750 Rockville Pike

Rockville, MD

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# *Introduction*

The HIV/AIDS epidemic in the United States (US) disproportionately impacts ethnic and racial minorities, the poor and other populations that are underserved by the health care system. Together, ethnic and racial minority populations make up close to thirty percent of the total population of the US.<sup>1</sup> However, these populations experience a disparate burden of HIV disease. In 2002 for example, ethnic and racial minority populations accounted for over three-fifths (61.6%) of the estimated number of persons living with HIV/AIDS in the US in 2002.<sup>2</sup> Despite the advances made in HIV clinical care and drug therapies, disparities in health outcomes and access to HIV treatment and care persist for ethnic and racial minorities living with HIV disease.<sup>3</sup>

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, originally enacted by Congress in 1990, and subsequently amended and reauthorized in 1996 and 2000, is due for reauthorization again in 2005. The CARE Act is administered by the United States Department of Health and Human Services (DHHS), Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB). The purpose of the CARE Act is to improve the quality and availability of care for low income, uninsured and underinsured individuals and families affected by HIV disease, reduce the use of more costly inpatient care, increase access to care for underserved populations, and improve the quality of life for those affected by the HIV/AIDS epidemic.<sup>4</sup> CARE Act funding is distributed through grants to states, local governments and private, non-profit organizations and institutions for primary health care and support services that enhance access to and retention in care; healthcare provider training; and technical assistance to assist funded programs address implementation and emerging HIV care issues.<sup>5</sup>

CARE Act funding also supports oral health treatment for individuals with HIV disease; development and evaluation of innovative HIV/AIDS service delivery models with potential for local and national replication, and time limited planning and capacity building grants to eligible public or private nonprofit entities, interested in developing, enhancing or expanding high quality HIV primary health care services in rural or urban un-served areas and communities of color.

On an annual basis the CARE Act programs reach over 500,000 persons. These programs are an important source of HIV care and support

services for ethnic and racial minorities living with HIV disease. In 2001, more than three fifths of the persons served by CARE Act programs were ethnic and racial minorities.<sup>6</sup>

During 2003, in preparation for the upcoming 2005 reauthorization of the CARE Act, the HIV/AIDS Bureau engaged in extensive consultation with constituents, the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment, national partners, frontline service providers, community members and people living with HIV/AIDS. This consultative process was designed to solicit broad feedback on current HIV/AIDS treatment and care issues and the future directions needed to improve and strengthen the Care Act. This process also included an examination of how well the Care Act is fulfilling its purpose of providing quality health care, treatment and crucial support services to low-income, uninsured, underinsured and underserved people living with HIV and AIDS.

## **Purpose of the Meeting**

As part of its on-going efforts to assure input from many diverse communities across the country, the HIV/AIDS Bureau convened, four, one-day meetings of representatives of different ethnic and racial minority groups in late January and early February 2004. This report summarizes the meeting held on February 3, 2004, with a group of Native American consumers, and service providers working on the frontlines throughout the United States to address the epidemic in their communities.

The purpose of the meeting was to elicit feedback from participants on:

- What is, and is not, working in the provision of HIV/AIDS care and treatment in their communities.
- The broader systems issues that impact access to HIV/AIDS care in their communities.
- The factors and special needs that must be taken into account to assure that Native American communities receive access to quality HIV/AIDS care and treatment.
- The unique characteristics of their communities, their healthcare needs, and the service delivery system(s) that need to be taken into account -- where the CARE Act fits within this broader framework.
- Strategies that the HIV/AIDS Bureau can undertake to reduce disparities in access to care through policy and guidance development, training, technical assistance, program development, program

management, and in formulation of recommendations for reauthorization

## Participants

The Native American Community Consultation Group was convened on February 3, 2004. This was a diverse group of seventeen (17) men and women, representing Native American people living with HIV disease, consumers of CARE Act services, community-based service providers and tribal organizations. The participants were from a cross section of cities and states that reflect some of the largest Native American population centers in the country. These included Anchorage, AK, Chinle, AZ, Phoenix, AZ, Tucson, AZ, Window Rock, AZ, Oakland, CA, Lumberton, NC, Albuquerque, NM, Buffalo, NY, New York, NY, Lawton, OK, and Oklahoma City, OK.

The service providers represent a wide range of entities providing services to different tribal groups, to Native Americans living on and off reservations, to Alaskan villages, and to those in rural areas or in urban areas. The types of organizations included tribal health programs, Native American community health centers, Native health boards, inter-tribal councils, community centers, professional health associations, and national, regional and local AIDS service organizations. These organizations serve diverse populations of Native Americans representing a wide range of tribal affiliations, and cultural and language groups. They serve the general Native American community and special needs populations including men who have sex with men, including gay and bisexual men, transgendered persons, at-risk youth, injection drug users, other substance abusers, women, and families. The organizations provide a wide range of services including culturally relevant primary health care for adults and children, OB/GYN services, prenatal counseling, confidential HIV-antibody testing and pre- and post-test counseling, AIDS treatment, traditional healing, STD testing and treatment, dental services, outreach services, home nursing, psychiatric treatment, referral and case management services, hot meals, food and clothing banks, health education, alcohol and substance abuse counseling and treatment, adult day care, employment training, counseling and job placement services, benefits assistance, legal services, advocacy, financial planning and emergency assistance, funeral and burial assistance, transportation, development and distribution of culturally sensitive AIDS education materials, individual and community level interventions for HIV and STD prevention, street outreach, individual and group counseling, retreats and support services for health providers and families, information dissemination on STD/HIV, Native health issues,

*Participants emphasized the importance of the primacy of group needs over individual needs as expressed by the centrality of the family and the tribal group.*

traditional healing practices, HIV prevention education, health professionals education and training, speakers bureaus, organizational capacity building, and training and technical assistance.

The participants represent a wide range of experience and expertise and included tribal leaders, community advocates, executive directors, program managers, nurses, social workers, case managers, outreach workers and peer educators. A number of the participants also had experience as members of Title I planning councils, Title II consortia, and as managers of Title III and Title IV grant programs.

# *Trends of HIV/AIDS among Native Americans*

An estimated 2,875 cases of AIDS among Native Americans have been reported to the Centers for Disease Control and Prevention (CDC) through December 2002. This represents 0.32% of the cumulative AIDS cases reported in the US. Native Americans accounted for 206 (0.48%) of the 42,136 new AIDS cases reported in 2002. However, the overall estimated AIDS case rates among Native Americans (8.5 per 100, 000 population) are 1.4 times the rates for whites (5.9). Among males the estimated AIDS case rates for Native Americans (16.9) are 1.37 times higher than the rates for white men (12.3). Among females, the estimated AIDS case rates for Native Americans (5.8) are 2.7 times higher than the rates for whites (2.1).<sup>7</sup>

Reports from the 39 areas, with confidential, name-based HIV reporting, indicate that Native Americans made up 1,042 (0.5%) of the 195,393 adult/adolescent cases of the HIV (not AIDS) reported in the US through December 2002. Moreover, Native Americans made up 141 (0.4%) of the 34,727 new cases of HIV (not AIDS) reported from these areas in the same year. In terms of gender, males accounted for nearly two-thirds (63%) and females accounted for over one-third (37%) of the new HIV (not AIDS) cases reported among Native Americans in 2002. In comparison among whites, males accounted for over four-fifths (83%) and females accounted for less than one fifth (17%) of new HIV (not AIDS) cases report in the same year.<sup>8</sup>

Among Native Americans males, men who have sex with men (MSM) accounted for the highest proportion of the new AIDS (47%) and new HIV - not AIDS (52%) cases reported in 2002. The leading exposure category among Native American women was heterosexual contact, accounting for 48% of the new AIDS cases and 40% of the new HIV (not AIDS) cases reported in 2002. Injection drug use followed closely accounting for 31% of the new AIDS and 33% of the new HIV (not AIDS) cases reported among Native American women in the same year.<sup>9</sup>

In 2002 there were 1,450 Native Americans estimated to be living with AIDS, accounting for 0.37% of the total 384,906 persons estimated to be living with AIDS in the US. Native Americans accounted for 1,565 or

0.56% of the 281,931 persons estimated to be living with HIV/AIDS reported from the 30 areas with confidential name-based HIV reporting. Males accounted for 78% of the estimated cases of Native Americans living with AIDS and 74% of those living with HIV/AIDS.<sup>10</sup>

The CDC conducted an in-depth analysis of AIDS among Native Americans from 1981-1997. This report showed that AIDS among Native Americans was geographically concentrated in selected areas in the West and in smaller cities and rural areas. Native Americans with AIDS were relatively younger than all persons with AIDS.<sup>11</sup> The states and metropolitan areas with the largest number of Native American persons living with AIDS are listed on the following table:

<b>Table1: Twelve States/Jurisdictions with the Highest Number of Native Americans Living with AIDS 2001</b>			
<b>Jurisdiction State/Territory</b>	<b># of Native Americans Living with AIDS at the end of 2001<sup>12</sup></b>	<b>MSA of Residence</b>	<b># of Native Americans Living with AIDS at the end of 2001<sup>13</sup></b>
California	260	Phoenix, AZ	72
Oklahoma	132	Los Angeles, CA	69
Arizona	124	Seattle, WA	59
Washington	100	San Francisco, CA	56
New Mexico	56	Tulsa, OK	46
North Carolina	54	Oklahoma City, OK	41
Texas	49	Minneapolis-Saint Paul, MN	34
New York	49	Riverside-San Bernardino, CA	29
Alaska	47	San Diego, CA	28
Florida	39	New York, NY	28
Minnesota	39	Albuquerque, NM	28
Illinois	27	Dallas, TX	26

Although the prevalence and incidence of HIV/AIDS among Native Americans have consistently been less than one percent, a number of factors such as misclassification, inadequate reporting, or low rates of HIV testing may mask the true extent and impact of the epidemic on this population. Misclassification of Native Americans to other racial/ethnic populations (i.e., to non-Hispanic white or Hispanic categories) has been documented and may result in undercounting. Other factors leading to undercounting include poor reporting of HIV and AIDS to states by the Indian Health Services' (IHS) facilities and tribal governments, lower frequency of HIV testing due to stigma,

personal shame, and distrust of the IHS and the federal and state governments. According to CDC, 55.8% of Native Americans 18-64 years of age reported never having been tested for HIV. There are variations by region with 58.1% of Native Americans living in the Southwest (one of the areas with largest number of Native Americans), reporting never being tested for HIV.<sup>14</sup> Moreover, because information about tribal affiliation of Native Americans is not collected by the HIV/AIDS surveillance system it is difficult to ascertain the variations in impact of HIV/AIDS among distinct ethnic sub-populations. The use of other data including surrogate markers for HIV-related risk behaviors (i.e. rates of other sexually transmitted diseases (STDs), alcohol, injection and other drug use); socio-economic indicators such as employment, poverty, and educational status; cultural/tribal affiliation; and trends in access to and utilization of health care could enhance understanding of the issues affecting HIV/AIDS trends among Native Americans.

## **Native Americans and the Ryan White CARE ACT**

CARE Act funded programs can provide an important source of care for uninsured and underinsured Native Americans living with HIV/AIDS. Native Americans can receive CARE Act services even if they are eligible for care from other sources such as IHS, tribal, or urban Indian health programs and services.<sup>15</sup> In 2001, based on data from the Annual Administrative Report, the percentage of Native Americans served by CARE Act programs was less than one percent. Title I funded programs served 2,844 (0.45%) duplicated Native American clients; Title II core services programs served 2,051(0.5%) duplicated Native American clients and approximately one percent of clients served by ADAP were Native Americans. Of the total number of clients served by Title III early intervention programs (EIS), 713 (0.46%) were Native Americans, and less than 1% of the clients served by Title IV funded programs were Native Americans.<sup>16</sup>

In addition to these programs Native Americans are served through the American Indian/Alaska Native (AI/AN) Initiative, a demonstration project funded under Special Projects of National Significance (SPNS) program of the CARE Act. HRSA/HAB funded this project in October 2002 for five years, to integrate substance abuse and mental health services with HIV care for American Indian and Alaska Native communities. The initiative consists of six demonstration projects and a technical assistance center.

*Elders share and teach  
traditional medicine and  
healing practices, and help  
youth to connect past  
experiences and responses to  
epidemics to the new challenges  
posed by HIV/AIDS.*

Native Americans face multifaceted social-economic and health problems that may contribute to inadequate access to HIV care. The complexity of these problems include higher rates of co-morbidities such as other sexually transmitted diseases, mental health and drug and alcohol problems, high rates of poverty, low educational attainment, poor housing and homelessness, present significant challenges for service providers. The need and demand for ancillary services to address these complex psycho-social and economic problems is underscored by data on service utilization patterns. For example, HRSA/HAB data on clients receiving services at CARE Act-funded programs shows that Native Americans are more likely than clients from other racial/ethnic groups to receive case management services (55 percent vs. 46 percent) and to receive housing assistance (35 percent vs. 25 percent).<sup>17</sup>

## Demographic Profile

The American Indian and Alaska Native population in the US is very diverse, and reflects significant variations by geographic distribution, tribal groups, and cultures. Native Americans speak over 200 indigenous languages and approximately 280,000 speak a language other than English at home.<sup>18</sup> The population of American Indians and Alaska Natives (AI/AN) totaled 4.1 million in 2000 according to the US Census Bureau. This figure, which constitutes 1.5% of the total US population, includes all persons who reported AI/AN alone or in combination with one or more other races. The total number of persons reporting AI/AN alone was 2.5 million or 0.9% of the total US population.

The AI/AN population (hereafter referred to as Native Americans<sup>19</sup>) is primarily concentrated in the West. In 2000, four out of 10 Native Americans lived in that region of the country. Nearly one third (31%) of the Native American population lived in the South, 17% lived in the Midwest, and 9% lived in the Northeast. More than half of all Native Americans lived in ten states: California (627,562), Oklahoma (391,949), Arizona (292,552), Texas (215,599), New Mexico (191,475), New York (171,581), Washington (158,940), North Carolina (131,736), Michigan (124,412), and Alaska (119,241). The only other state with a Native American population larger than 100,000 was Florida (117,880). These eleven states represented 62% of the total Native American population.<sup>20</sup>

Native Americans were the majority of the population in 14 counties in the West and 12 counties in the Midwest. In the West, these counties are in four states: Alaska, Arizona, Montana and Utah. In the Midwest, the counties are in four states as well: South Dakota, Wisconsin, North

Dakota and Nebraska. The Native American population in the US is primarily concentrated in urban areas (66%). About one million Native Americans (24.9%) live on reservations and in Census defined tribal areas. The rest live in other rural geographical areas.<sup>21</sup>

Of all places in the US with 100,000 or more population, New York, NY and Los Angeles, CA were the cities with the largest Native American populations: 87,241 and 53,092, respectively. Of the top ten largest places in the US, Phoenix, AZ (2.7%) had the largest proportion of Native Americans, followed by Los Angeles, CA (1.4%), San Diego, CA (1.3%) and San Antonio, TX (1.3%).

The top ten places of 100,000 or more population, with the largest populations of Natives Americans were: New York, NY, Los Angeles, CA, Phoenix, AZ, Tulsa, OK, Oklahoma City, OK, Anchorage, AK, Albuquerque, NM, Chicago, IL, San Diego, CA, and Houston, TX. Five of these cities were in the West (Los Angeles, Phoenix, San Diego, Anchorage, and Albuquerque). Of these places, the cities with the highest proportion of Native Americans were Anchorage (10.4%) and Tulsa (7.7%).<sup>22</sup>

**Table 12: Ten Largest Places in Total Population and in Native Americans Population - 2000**

Place 100,000 or More Population	Total City Population		Total Native American*		Percent of Total City Population
	Rank	Number	Rank	Number	Percentage
New York, NY	1	8,008,278	1	87,241	1.1
Los Angeles, CA	2	3,694,820	2	53,092	1.4
Chicago, IL	3	2,896,016	8	20,898	0.7
Houston, TX	4	1,953,631	10	15,743	0.8
Philadelphia, PA	5	1,517,550	21	10,835	0.7
Phoenix, AZ	6	1,321,045	3	35,093	2.7
San Diego, CA	7	1,223,400	9	16,178	1.3
Dallas, TX	8	1,188,580	18	11,334	1.0
San Antonio, TX	9	1,144,646	12	15,224	1.3
Detroit, MI	10	951,270	25	8,907	0.9
Oklahoma, OK	29	506,132	5	29,001	5.7
Tucson, AZ	30	486,699	11	15,358	3.2
Albuquerque, NM	35	448,607	7	22,047	4.9
Tulsa, OK	43	393,049	4	30,227	7.7
Anchorage, AK	65	260,283	6	26,995	10.4

\* This number includes Native Americans alone or in combination with other races

In 2002, the Bureau of Indian Affairs published a list of 562 federally recognized tribes in the US, including 223 village groups in Alaska. "Federally recognized" means these tribes and groups have a special, legal relationship with the U.S. government. This relationship is referred to as a government-to-government relationship.<sup>23</sup> There are other tribes that are not federally recognized but may have state recognition. Still other tribes have neither federal nor state recognition. According to the Census 2000 data, approximately 74% or 3.1 million of the people

reporting Native American either alone or in any combination with other races, identified tribal membership. The largest tribal groupings with 100,000 or more people are Cherokee, Navajo, Latin American Indian, Choctaw, Sioux and Chippewa. Together, these six tribes account for 42% of all persons identifying a tribal affiliation in 2000. The largest tribal grouping specified was Cherokee, followed by Navajo and Latin American Indian.<sup>24</sup>

**Table 3: Ten Largest Native American Tribes: 2000**<sup>25</sup>

Tribal Grouping	Population
Cherokee	729,533
Navajo	298,197
Latin American Indian	180,940
Choctaw	158,774
Sioux	153,360
Chippewa	149,669
Apache	96,833
Blackfeet	85,750
Iroquois	80,822
Pueblo	74,085

In 2000, Eskimo (54,761) was the largest Alaska Native tribal grouping reported alone or in any combination. Tlingit-Haida (22,365) Alaska Athabascan (18,838) and Aleut (16, 978) followed.<sup>26</sup>

## Socio-economic Status and Access to Health Care

Native Americans are disproportionately affected by many social and behavioral problems that are associated with health disparities and contribute to vulnerability for HIV infection. The Native American population is relatively young, has high rates of poverty, lower educational attainment, and inadequate access to health care. Native Americans also experience disproportionately high rates of sexually transmitted diseases, drug and alcohol abuse, and depression.

Native Americans fare poorly on a number of socio-economic indicators, such as educational attainment, labor force participation and poverty, when compared to whites in the US. Less than three quarters of

Native American (70.9%) adults 25 years and older were high school graduates or more, in 2000, compared to 83.6% of whites. In 2000, a little over one tenth of Native Americans (11.5%) reported having earned a bachelor's degree or more, compared to over one quarter of whites (26.1%).<sup>27</sup> In terms of labor force participation, Native Americans had the lowest percentage of labor force participation. In 2000, 60% of Native Americans, 20-64 years of age, were employed compared with 74.1% of whites. Moreover, the percentage of people unemployed was highest among Native Americans (7.6%). In contrast, whites had the lowest unemployment rate (3%). Native Americans also had the highest proportions of people living in poverty of all ethnic/racial groups in the US. Over one quarter (25.7%) of the Native American population was living in poverty in 1999, compared to less than one-tenth of the white population (8.1%).<sup>28</sup>

Native Americans experience persistent health disparities. Mortality rates for Native Americans are significantly higher than for whites across each stage of the life span. Death rates (per 100,000 population) for Native Americans 0-14 years of age were 78.3 compared to 55 for whites. For persons ages 24-44, the rates were 227.4 for Native Americans compared with 141.7 for whites. Among those aged 45-64, the death rates were 729.2 for Native Americans and 619.9 for whites.<sup>29</sup> According to a recent study by the CDC, Native American communities bear a greater burden of health risk and chronic disease than other racial/ethnic minority populations. When compared to African Americans, Latinos and Asians, Native Americans had the highest prevalence of obesity, current smoking, cardiovascular disease, and diabetes. However, a substantial percentage of Native Americans received preventive services related to high blood pressure, diabetes, cervical cancer, and vaccinations for influenza and pneumonia.<sup>30</sup> Native Americans are also over represented among high need populations such as the homeless, people with drug, alcohol and mental health problems, and people exposed to trauma and violent victimization.<sup>31</sup>

Health care for members of Native American tribes is provided by a system apart from the mainstream American health care delivery system. The federal government has a trust responsibility, based on treaty obligations and federal statutes, to provide health care to members of federally recognized tribes. DHHS' Indian Health Service (IHS) is the federal agency responsible for providing health care to Native American populations. The IHS provides health care services directly to Native Americans through their own health centers and hospitals, indirectly through tribally managed health services, and through the Urban Indian health programs it funds.

However, not all Native Americans are eligible for IHS services. IHS eligibility rules limit its service population to about 1.5 million of the 4.1 million Native Americans in the country. Moreover, many who may be eligible for IHS service do not live in areas where the IHS facilities are located (mostly on reservations, in rural areas).<sup>32</sup>

*The perception that HIV/AIDS is a "white man's disease" like many other infectious diseases that Native Americans have been exposed to by whites, reinforces mistrust and may influence Native Americans' willingness to get tested for HIV.*

There are other sources of health care coverage for Native Americans. For example, Native Americans also qualify for private health insurance and other sources of publicly financed health coverage or services. About 49% of Native Americans have employer based health coverage, and 17% of Native Americans are covered by Medicaid. Medicaid provides coverage for more than one quarter low income Native Americans (28%). However, more than one-third (35%) of Native Americans are uninsured. The rates of uninsured are highest among low income Native Americans (48%).<sup>33</sup>

A recent study on health service access, use, and insurance coverage among Native Americans, found that Native Americans had less insurance coverage and worse access and utilization than whites. Moreover, more than half of low-income, uninsured Native Americans did not have access to the IHS. The study also found that among the low-income population, Native Americans with only IHS access fared better than uninsured Native Americans, and as well as insured whites for key measures. However, these Native Americans received less preventive care. The study found that while the IHS partially offsets lack of insurance for some uninsured Native Americans, crucial needs are likely to be unmet. This suggests that Native Americans without health coverage will continue to face significant problems in accessing health care and preventive services, despite the services offered by the IHS.<sup>34</sup>

Native Americans living with HIV/AIDS experience complex socio-economic, political, and cultural and linguistic barriers to access to HIV/AIDS services. These access barriers are compounded by tribal sovereignty, the government-to-government relations of Native American tribes to the federal government, and the role of the Indian Health Services in providing health care to members of federally recognized tribes. Further complicating access to HIV/AIDS services are issues related to the size, geographic distribution, and tribal, cultural and linguistic diversity of the Native American population. The combination of diversity and complexity of the multiple factors affecting access to care for Native Americans sub-groups present formidable challenges to program planners and service providers in the design, implementation, and delivery of culturally and linguistically appropriate HIV prevention and care services. The Native American Community

Consultation Group identified specific issues and barriers to access to care faced by Native Americans living with HIV/AIDS in their communities. These issues are discussed in detail in the next sections of this report.



# *Meeting Proceedings*

On February 3, 2004 HRSA's HIV/AIDS Bureau convened the Native American Community Consultation Group meeting. The National Minority AIDS Council (NMAC), in partnership with HAB, assisted in identifying participants for the meeting and arranged the meeting, travel and lodging logistics. The meeting was held at the Doubletree Hotel and Executive Meeting Center, in Rockville, Maryland, from 9:00 AM to 4:00 PM. The full report of the meeting is included in the appendix of this report.

Dr. Deborah Parham Hopson, Associate Administrator of the HIV/AIDS Bureau, welcomed the participants and then provided an overview of HAB's rationale and objectives for the meeting.

Ms. Idalia Sanchez, Acting Director of HAB's Office of Policy and Program Development (OPPD), welcomed the participants and then expanded on Dr. Parham Hopson's description of the purpose of the meeting. In Steven Young's absence, Ms. Sanchez also provided an overview of the Ryan White CARE Act.

Both speakers opened the floor to questions from the attendees following the opening presentations. A detailed description of the presentations and questions and answers may be found in the appendix of this report.



# *A Community Window*

Mr. Kilkelly, a consultant who facilitated the meeting, introduced and handed out the tool "A Community Window...HIV/AIDS Care from My Point of View". This tool was used to structure and guide the discussions throughout the remainder of the day, on the focus question:

**What is necessary to achieve better access to quality HIV/AIDS care through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act at the community level?**

The discussion was divided into three segments that required participants to work individually, and then in small groups, to address the focus question in the context of identification of:

- Community Strengths
- Community Challenges
- Barriers to, and Facilitators of, HIV/AIDS Care

Following each segment, the small groups presented the outcomes of their deliberations to the larger group and a broader discussion of the issues ensued. The facilitator stated that it was important to acknowledge the diversity of the communities represented (race/ethnicity, geography, etc.). He asked participants to define what they meant by "community" and to share that definition with the larger group when they reported out. A fuller description of the meeting process is included in the appendix of this report.



# *Key Findings*

This section summarizes the key issues that the participants identified regarding community strengths and challenges, and the barriers to, and facilitators of, HIV/AIDS care in their communities.

## **Definition of Community**

The group identified community in various ways:

- HIV service providers and consumers
- Tribal and cultural groups with ties across large geographic areas
- Urban and rural communities

## **Community Strengths**

The participants identified the following community strengths:

### **Socio-cultural Factors**

#### **Diversity**

- Tribes
- Cultures
- Languages
- Religions

#### **Language**

- Integral to the culture(s)
- Tribal groups have distinct languages

#### **Strong Cultural Traditions and Heritage**

- Respect for and veneration of elders
- Traditional medicine and healing practices

#### **Faith - Spirituality**

- Spirituality (4 equal parts - life, unity, equality, and eternity)
- Spiritual healing

### **Holistic Worldview**

- Look at things comprehensively, not compartmentally
- Holistic wellness approaches increase access

### **Humor**

- Ability to laugh (Indian humor)
- Helps in coping with adversity

### **Resiliency**

- Developed in response to historical oppression
- Assures survival and responses to new challenges

### **Focus on Community vs. Individual**

- Family includes extended family members
- Tribe

### **Social Systems and Social Cohesiveness**

- Close-knit community
- Caring individuals
- Encourages united response to external threats
- Small interconnected networks facilitates members' ability to speak for all NA needs

## **Socio-political Factors**

### **Strong Tribal Sovereignty**

### **Self Determination**

### **Strong Leadership**

- Political leaders provide support via legislation
- Traditional and Tribal leaders
- Melvin Harrison and other people in the field (care enough to do the work)
- Strong civic ties (rely on relationships with others in the community and in HIV field)
- Community mobilization (Navajo Nation is using MAPP community mobilization process)

## **Care Services System**

### **Available Resources**

- Tribal
- State
- Community based organizations (CBOs)
- Accessible to people on or around the reservation

### **Knowledgeable People**

#### **Health Providers**

- Public health nurses (PHNs)
- Community health representatives (CHRs)

#### **Integration of Culture into Health Programs**

- Existing diabetes prevention programs
- Other programs

#### **Collaborative Networks**

- HRSA/SPNS
- Native American Health Management Alliance (HMA) provides access throughout the state
- First NA Title III program in Alaska complements IHS services

#### **Connecting HIV to Past Epidemics**

- Elders' knowledge of past responses to epidemics transferred to youth
- Helps bridge past experiences to current responses to HIV epidemic

#### **Participation in HIV Planning Processes**

- Community organizing - exploring development of an HIV planning group for the Navajo nation
- Strong consortium (CPG)

## **Discussion**

Participants discussed the diversity of Native Americans throughout the US as a major strength. This diversity is expressed in the hundreds of different tribes, both federally recognized and not, that exist, and Alaska villages. Moreover, the different tribal groups may also have different cultural values, beliefs, practices, and languages. The different languages are integral to the distinct cultures. Although the diversity is certainly viewed as a strong point, it can also present enormous challenges to delivery of, and access to, services.

The participants emphasized the importance of the primacy of group needs over individual needs as expressed by the centrality of the family and the tribal group. Family includes a network of extended kin and clan members who participate in raising children, and serve as surrogate parents through informal adoption practices. Both family and community members can provide support to the individual in time of need, and there is an expectation of reciprocity and commitment to the well-being of the group as a whole. The cohesiveness of family and tribal networks is a factor that has enhanced the overall survival of Native Americans despite hundreds of years of oppression.

Native Americans have strong cultural traditions and a rich heritage that strengthen their capacity to respond to the threats posed by health and social problems. Respect and veneration of elders is a key feature across tribal groups. Elders, through the tradition of story telling, pass on the knowledge, traditions, culture, history, and experiences of the tribal groups from generation to generation. Elders share and teach traditional medicine and healing practices, and help youth to connect past experiences and responses to epidemics to the new challenges posed by HIV /AIDS. This provides continuity and reinforcement of important cultural traditions. Spirituality is also central to Native American life, and provides the basis for both physical and emotional healing. Tied to this is a holistic world view that connects health and wellness to the harmony of mind, spirit, and body with nature. Illness implies disharmony (imbalances) within the person and with his or her universe. This implies that the whole individual must be treated, not just a part of his or her body. The holistic view of wellness thus requires an integration of approaches that address the physical, emotional, mental and spiritual aspects of healing.<sup>35</sup> However, there are some variations in spiritual beliefs across Native tribal and cultural groups that must be taken into account when providing care.

The participants identified the ability to laugh and see the humor in situations strengths. Humor provides a mechanism to cope with the past and present traumas, losses, and adversities experienced by Native Americans. Connected to this is the resiliency to persevere despite suffering historical traumas and current oppression.

Participants agreed that Native American social structures and systems support social cohesion. They viewed this cohesion as a positive attribute, particularly in responding to external threats. Although there may be many intra- and inter-tribal conflicts dividing them, when faced with external challenges that threaten the well-being of the Native

American community as a whole, they are able to put their differences aside to respond as a unified force. The close-knit nature of the Native American community also allows service providers and advocates to know and to represent the interests of the overall community when they participate in external activities where they may be the only Native American present.

Participants affirmed the importance of tribal sovereignty and self-determination in Native American communities. Native nations in America were self governing prior to contact with European states. Native American tribes maintain their sovereignty today. However, the degree of sovereignty may vary depending on the factors such as the degree of cultural assimilation to mainstream culture, and the outcomes of past disputes about tribal self-government. Since sovereignty affects the options available to a tribe in providing health care to its members, the degree of sovereignty a tribe has can influence the health care available to its members.<sup>36</sup>

Participants agreed that strong leadership exists within different sectors of the Native American community. Tribal, political, civic, and community leaders provide voices and support for Native American health concerns. There are, for example, Native American politicians, as well as other politicians, who support legislation and funding promoting Native health and welfare. There are also well known Native American leaders in the AIDS arena that have been effective advocates. There are strong ties to other civic organizations and to the HIV/AIDS community. There are also community mobilization efforts underway to generate greater Native American participation in HIV and health planning in general. Navajo Nation, for example, is employing a community coalition building and mobilizing strategy - Mobilizing for Action through Planning and Partnerships (MAPP) - to address STDS and HIV in an integrated fashion in their community.

The participants noted a number of resources within their communities that strengthen their ability to respond to HIV. These include the resources of tribal governments, states and community based organizations (CBOs). The presence of CBOs that provide care related services on, or near, reservations enhances access to health care and other services. In addition government funding provides support for needed services. Native American communities have a pool of knowledgeable people including health care providers such as physicians, public health nurses (PHNs) and community health representatives (CHRs), who can provide care.

*There are also other pressing and competing health and social matters such as drug and alcohol abuse, depression, diabetes, suicide and poverty that draw community members' attention.*

Another asset highlighted by participants is the ability of Native programs to integrate cultural beliefs, norms, values, traditional medicine, and healing practices into health care programs. The diabetes prevention programs that exist in many Native American communities are an example.

A number of collaborative networks such as the projects funded by the HRSA SPNS initiative and the Native American Health Management Alliance (HMA) in New Mexico exist in Native American communities and serve to increase access to health care. For example, the Native American HMA allows Native Americans within the state to access health services, regardless of where they live in the state. Alaska has received funding under Title III for the first time to provide EIS services. This program is the first Title III program for Native Americans in Alaska. It is an example of successful collaboration between CARE Act programs and the services provided by the IHS.

The participants emphasized the importance of Native American participation in HIV planning processes in facilitating access to care services by the Native American community. While there are variations in the degree of such participation across Native American communities, in Title I planning councils, Title II consortia and HIV prevention community planning groups, the participants agreed that participation in these bodies is a vehicle for the communities' voices to be represented and heard. By strengthening the degree of such participation, community representatives can play significant roles in advocating for and assuring more services that are responsive to the unique needs of diverse Native American communities.

## **Community Challenges**

The participants identified the following factors as contributing to the challenges faced by their communities.

### **Socio-cultural**

#### **Acceptance**

- Fatalism
- Resignation

#### **Language**

- Diversity of languages spoken by distinct Native American groups
- Intergenerational differences in language

## **Stigma/Homophobia**

- Social taboos
  - Sexuality
  - Homosexuality

## **Lack of Community Involvement and Support**

- Community people are caring and available but don't want to get involved
- Lack of community readiness and involvement to work on HIV issues

## **Socio-economic**

### **Poverty**

### **High Unemployment**

### **Lack of Education (both urban and on the reservation)**

### **Isolated Rural Areas**

- Isolation of providers
- Turnover of providers

### **Lack of Transportation**

- Difficulties traveling over long distances to reach services
- Especially in rural areas and reservations

## **Socio-political**

### **Tribal Status**

- Recognition issues for tribes (state vs. Federal)

### **Lack of Support from Politicians and Tribal Leadership**

- Lack of recognition of the problem due to low indices of morbidity and mortality
- Funding is not forthcoming
- NA leaders also do not recognize HIV as a problem
- Lack of tribal policies to address HIV issues
- Lack of political power

## **Care Services System**

### **Cultural Barriers**

#### **Lack of Cultural Sensitivity and Competency**

- Traditional and spiritual beliefs values in competition with public health and Christian values
- Inadequate numbers of culturally competent providers

#### **Mobility of Target Population**

- Urban to rural
- Rural to urban

#### **Competition between HIV and Other Pressing Health Issues**

- Substance abuse, mental health, diabetes etc. compete with HIV for funding and services
- IHS does not track how HIV funds are spent in community
- Dual addictions (alcohol/ other drug abuse)
- Connection of co-occurring problems to high-risk behaviors (child sexual abuse, domestic violence, depression, etc.)

#### **Breaches in Confidentiality**

#### **Lack of Integrated Services**

#### **Lack of Access to HIV Care, Treatment and Dental Services**

#### **Lack of Native American Service Providers**

- Non-Indian CBOs, ASOs
- No native-specific treatment centers
- Lack of services specifically tailored for Native Americans
- Coordination of benefits is difficult dealing with non-Native agencies

#### **Limited Collaboration among Providers**

#### **Tokenism**

- Just want to see us at the table
- Don't want to hear us

#### **Organizational Infrastructure**

### **Lack of Diversified Funding**

- Reliance on IHS funding
- Absence of proactive fund development

### **Lack of Infrastructure**

- Lack of resources
- Most communities lack people with educational and skill level to provide services
- Lack of Native American, Alaskan Indian, Native Hawaiian case managers
- Significant demand for case management with limited funding and services

## **Discussion**

The participants identified a number of community challenges related to socio-cultural issues. Acceptance of HIV/AIDS as yet another epidemic brought on by the "white man", coupled with cultural beliefs that talking about a disease will bring it on, reinforces fatalistic views. This presents significant challenges to efforts to increase HIV testing and link those diagnosed with HIV infection to care.

The diversity of languages spoken by Native Americans also presents significant challenges to access to, and delivery of, care. HIV and AIDS may not have meaning in indigenous languages. As a result these conditions cannot be discussed in local indigenous languages, nor can indigenous healing processes be applied to them

### **Stigma and Homophobia**

Social taboos related to sexuality and homosexuality present challenges to acceptance of HIV/AIDS and affect prevention and care efforts. Although many Native tribes accepted a broader range of gender roles and sexual expression, the penetration of Christianity introduced or strengthened negative attitudes regarding homosexuality and sexual expression. There are taboos and inhibitions related to discussion of sexual matters. Moreover, the perception that HIV/AIDS is a "white man's disease" like many other infectious diseases that Native Americans have been exposed to by whites, reinforces mistrust and may influence Native Americans' willingness to get tested for HIV. Many Native American communities are isolated, small, and tight-knit. On many reservations, talk of HIV disease is taboo. The lack of confidentiality in IHS clinics also deters many Native Americans from being tested because of fear that their HIV positive status will be disclosed and that they will experience associated stigma and discrimination.

*Tribal leaders do not see HIV as a major problem and are reluctant to target resources to HIV/AIDS services because the data show HIV/AIDS morbidity and mortality to be relatively low when compared to other health issues affecting Native Americans.*

### **Lack of Community Involvement and Support**

The lack of community involvement in HIV/AIDS issues and lack of support were identified as a major challenge. Participants noted that community members are caring people but are reluctant to become involved in HIV for a number of reasons including the stigma associated with the disease. People may not become involved because of the shame associated with HIV and fear of how individual involvement will bring shame to their families and the community as a whole. There are also other pressing and competing health and social matters such as drug and alcohol abuse, depression, diabetes, suicide, and poverty that draw community members' attention. Some participants discussed strategies to generate greater community involvement by having elders involved and participating in education of the younger generations. One participant said that "elders are the foundation of our understanding of life". Elders are respected and able to pass on knowledge and experience to younger generations. Others said they had difficulty engaging elders in educational and community mobilization efforts because so much information is taboo and "creates secrets". In Alaskan villages, for example, talk about sex is taboo, and strategies that work in urban settings are not applicable. One participant said that in Alaska an approach used was to discuss past epidemics (smallpox, TB) that elders are familiar with as a way to connect their knowledge and open up discussion of the current epidemic of HIV.

### **Socio-economic Conditions**

A number of socio-economic factors were identified and significant community challenges. These included high unemployment rates and the resulting poverty, as well as low educational attainment. The high rates of morbidity and mortality among Native Americans are associated with the adverse consequences of poverty, including lack of health insurance and limited access to health care. Educational level affects an individual's ability to understand and apply health related information. Lack of HIV education both in urban area and on the reservation is also a major challenge.

Many Native Americans live in isolated rural areas cutting them off from services and resources. There are few HIV service providers working in these rural areas and the isolation can lead to burnout and staff turnover. Lack of transportation is a major challenge in rural areas, reservations and Alaska villages. In many rural areas, clients must travel long distances to get to a service site. A worker may have to spend the whole day traveling to visit a client and attempt to link him or her to other services. Persons living in remote Alaskan villages may need to be flown to Anchorage or other large cities to receive services.

## **Socio-political Factors**

Other challenges are related to socio-political issues. Tribal status is a major issue because not all Native American tribes have federal recognition. Lack of federal recognition can limit access to health services and resources because IHS health services are limited to members of federally recognized tribes. Moreover, the widely held misconception that Native Americans are not citizens of their state, and therefore, ineligible for state programs and benefits because they are part of a tribe, serves to limit access to care. In fact, Native Americans, as US citizens, are eligible to participate in all public, private, and state health programs available to the general public.

Another challenge is the lack of support from tribal leaders and politicians for HIV/AIDS. Tribal leaders do not see HIV as a major problem and are reluctant to target resources to HIV/AIDS services because the data show HIV/AIDS morbidity and mortality to be relatively low when compared to other health issues affecting Native Americans (diabetes, suicide, alcoholism, TB, etc.). One participant commented that the use of national data is problematic for planning and resource allocation purposes because the data does not reflect the true degree of HIV's impact on Native Americans, or the extent of the disparities. The Native American population is small and it is also dispersed throughout many states. The participant suggested that other indices of disparities be used to show the disproportionate impact of many health related and social problems on Native American populations.

There is also a lack of or inadequate tribal policies to deal with HIV issues (ex. no blood-borne pathogen training). On the Navajo reservation, existing tribal law imposes jail sentence for transmitting STDs. In Alaska, tribal policy requires all pregnant women to be tested for HIV. The focus is on the women and not the men who are getting them pregnant.

Another issue that presents major challenges is lack of political power. Many Native Americans do not vote in elections because they view the process as one of the US government, and not "their" government. In addition, tribal leaders ask members not to vote. As a result, Native Americans have no voice in the system or pull with politicians. One participant observed that some tribes do not want to take Federal funds (Iroquois in NY). Moreover, each individual nation in the Six Nations is not the same, yet federal programs such as the CARE Act have generic funding formulas that do not correspond to the diversity of Native American tribes.

## **Care Services System**

### **Cultural Barriers**

Participants identified cultural barriers as major challenges to access. One barrier mentioned was related to encounters between providers and Native American clients where the providers are more focused on completing paperwork rather than on the clients' needs. One participant noted that in predominately white CBOs, rather than trying to build a relationship with the client, providers will focus on completing documentation related to service eligibility or intake information. Native American clients find this behavior alienating and dehumanizing. Such approaches deter people from seeking services.

Another example illustrated the importance of sharing food for Native Americans. In Native American gatherings, food is central and serves as a means to build relationships and a sense of community. However, under the guidelines of the CARE Act, food cannot be purchased for meetings (allowable funds are not sufficient). One participant noted that this restriction needs to be revised to be more sensitive to Native American culture.

### **Lack of Cultural Sensitivity and Competency**

Lack of cultural sensitivity and competency of service providers was another major challenge identified. They noted, for example, that traditional Native American values often come into conflict with the values underlying the public health system and with Christian values. For example, Native beliefs about the value of traditional medicines and healing services may be viewed as "primitive" and dismissed by providers trained in western medicine. Another example is providers' lack of understanding of the historical traumas suffered by Native Americans at the hands of the "white man", and how they relate to present high-risk behaviors such as injection drug use, alcohol and other substance abuse, sexual assault, and abuse.

### **Other Pressing Problems**

Native Americans experience other pressing health problems such as diabetes, unintentional injuries, alcoholism, and substance abuse. In many Native communities, these health problems are reaching crisis proportions and tribal leaders are concerned that Native health resources may not be adequate to deal with the enormous needs. Competition for limited resources is therefore a major challenge to HIV prevention and care efforts, especially since many tribal leaders may not view HIV as a threat due to low incidence and prevalence among Native Americans. Participants also noted that the IHS does not track how HIV funds are

spent in Native communities and there is little accountability for this funding. Dual addictions (alcohol and other substance abuse) further complicate the health problems and service needs of Native Americans. Moreover, co-occurring problems such as child sexual abuse and domestic violence increase vulnerability for HIV infection among Native American children, youth, and women.

Providers are faced with a multitude of challenges due to the enormity and complexity of the problems and very often are at a loss for how to address such behaviors and conditions (substance abuse, violence and child sexual abuse) which contribute to greater risk taking and therefore risk for HIV infection.

### **Historical Traumas**

Some participants observed that the preponderance of health and mental health problems faced by Native Americans today have their roots in the historical traumas experienced by Native peoples as a result of the policies of conquest, assimilation, and termination carried out by the federal government. These policies resulted in death of generations elders to infectious disease and war, forced relocation to reservations, and the loss of ancestral lands. They also led to the forcible removal of Native children from tribes to attend boarding schools; the physical, sexual and emotional abuse of children in boarding schools; lack of parenting; and historical grief from this trauma. The policies prohibited the use of Native languages, religious practices, traditional medicines and philosophies, and forced migration to urban areas to promote assimilation. Participants noted that these historical traumas have contributed to the relatively high rates of alcoholism, depression, suicide, child sexual and physical abuse, and domestic violence in Native communities.

They agreed that it is important to understand these historical traumas and their impact on different Native communities. They noted that each community is very different. "In some communities things have been bad for so long -- things are so broken -- that it is hard to put it back together. There are no easy answers." Participants also observed that these issues are not unique to Native Americans and that other ethnic and racial minority groups in this country have had parallel experiences of cultural genocide. They affirmed the importance of spirituality in dealing with these problems.

### **Mobility of the Population**

Participants also identified the mobility of Native Americans as a significant challenge to providing care and assuring continuity. Many

Native Americans may travel between reservations and rural areas and urban areas for family visits, tribal ceremonies, employment, educational opportunities, or to access services that are unavailable where they live. The movement back and forth between reservations and rural areas or urban areas can affect disease transmission and prevention efforts.

### **Breaches in Confidentiality**

As previously noted, breaches in confidentiality were identified as a major challenge to access to care for Native Americans. Confidentiality breaches are due to the close knit nature of many Native American communities, where many health providers are also members of the family or tribe and know the identities of persons who are living with HIV/AIDS. There is also lack of confidence in IHS facilities where many breaches of confidentiality occur.

### **Lack of Integrated Services**

Participants agreed that the interconnectedness of many of the health and mental health problems faced by Native Americans requires a holistic approach to services that integrates primary health care, HIV/AIDS prevention and care, alcohol and substance abuse treatment, mental health services, and other ancillary services. The holistic world view that connects health and wellness to the harmony of mind, spirit, and body with nature also needs to be integrated into the approach to services. However, a number of factors create obstacles to integration. These include the lack of resources, the inadequate funding of IHS facilities, the lack of trained providers, the variations in size of IHS and tribal health facilities, and the remoteness of location of some facilities.

### **Lack of Access to HIV Care, Treatment and Dental Services**

Participants noted that there is an overall lack of available HIV care and dental services in Native American communities. This creates tremendous barriers to access. This is especially true for persons living in rural areas, on or off reservations. Many clients will have to travel long distances over long periods of time to receive care. The situation is most pronounced in Alaska, where air travel is required to transport clients living in remote villages to care facilities in Anchorage or other large cities.

### **Lack of Native American Service Providers**

The participants also identified the lack of trained Native American service providers and service organizations as a major challenge to access. There are a number of non-Native American CBOs and ASOs that serve Native Americans. However, the cultural barriers and lack of cultural competency previously discussed remains a challenge to access

for Native Americans receiving services through such providers. Some of these agencies may have Native American employees but they may not provide direct services to clients. In addition, there is a lack of Native - specific drug and alcohol treatment centers.

Coordination of benefits is difficult for Native American patients because the IHS has a policy of payer of last resort. This policy requires Native American patients to exhaust all health care resources available to them through private insurance, state health programs and other federal programs before IHS will pay for services through the Contract Health Service (CHS) program. However, other agencies such as the CARE Act funded ones and state funded services may also claim to be payer of last resort. The complexity of financing for health care often makes it hard to get patients into needed services.

Other challenges to access included lack of collaboration among providers, lack of representation of Native Americans in key policy positions and at HIV planning tables (tokenism - just want to see us at the table, don't want to hear us).

### **Lack of Funding and Infrastructure**

Funding and infrastructure issues were also identified as key challenges to access. The IHS experiences severe funding challenges that limit their ability to provide the level and scope of services needed by eligible Native American clients. Native American CBOs and ASOs rely on IHS funding and lack diversified funding bases. There is a lack of proactive fund development being carried out by many of these organizations to access other sources of funding to support their services. These organizations also lack an adequate pool of trained Native American staff to deliver case management health and behavioral health services. There is a high demand for case management services, but organizations lack the resources and trained staff to meet that need. The lack of trained professional providers is directly related to the lower educational attainment in Native American communities.

## Barriers to, and Facilitators of, HIV/AIDS Care

The participants identified the following factors as barriers to, and facilitators of, access to HIV/AIDS care in their communities:

### Geographic Factors

Barriers	Facilitators
<p><b>Rural vs. Urban</b></p> <ul style="list-style-type: none"> <li>• Rural isolation</li> <li>• Many programs are urban based and/or developed - urban based programs are not appropriate for reservations, rural areas</li> </ul>	<ul style="list-style-type: none"> <li>• Increase rural doctors</li> <li>• Expand services on or near reservations</li> </ul>

### Socio-economic Conditions

Barriers	Facilitators
<p><b>Lack of/ Inadequate Transportation</b></p> <ul style="list-style-type: none"> <li>• Distance to care sites is great, particularly in rural areas</li> </ul>	<ul style="list-style-type: none"> <li>• Increase use of telemedicine</li> <li>• Increase mobile care sites</li> <li>• Provide funding to use airlift</li> </ul>
<p><b>Poverty</b></p> <ul style="list-style-type: none"> <li>• High unemployment</li> <li>• Basic needs unmet</li> </ul>	<ul style="list-style-type: none"> <li>• Increase training and job opportunities</li> <li>• Address poverty</li> </ul>
<p><b>Co-Occurring Conditions</b></p> <ul style="list-style-type: none"> <li>• Drug/alcohol use/abuse</li> <li>• Substance abuse, mental health issues</li> <li>• Other compounding issues (housing, domestic violence, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• Address stigma related to these problems</li> <li>• Provide culturally appropriate treatment that addresses these issues within the context of historical traumas</li> </ul>

**Socio-cultural Factors**

**Barriers**

**Language (diversity)**

**Individual Clients**

- Unique issues
- Complexity of problems

**Racism, Elitism**

- Both internal and external
- Issue of full blood vs. half blood - an issue for the NA community to deal with
- Internal racism (half bloods, being from Canada, etc)

**Facilitators**

- Train and utilize Native American peers to conduct outreach and provide services
- Utilize tribal elders to provide education (oral history)
- Train larger pool of bilingual/bicultural Native American care providers and staff
- Speakers bureau
- Incorporate Native traditions in outreach, education and care
  
- Increase pool of Native American case managers through training
- Develop effective linkage agreements and MOUs (not just on paper) with non-Native service providers to coordinate multiple services
- Increase effective collaborations on Native issues with state, CBOs and Native service organizations
  
- Provide training to service providers on eligibility for tribal enrollment and IHS services
- Coordinate efforts between IHS, tribes and urban programs to clarify eligibility issues
- Provide education to service providers to dispel myths and clarify issues related to tribal ancestry
- Provide education and training to address internal racism

## Socio-cultural Factors

### Barriers

#### Sexism

#### Community perceptions of HIV/AIDS

- No community awareness
- Apathy and ignorance

### Facilitators

- Speakers Bureau (many of us have clients that are "out." Can target communities with people that look like them, speak like them)
- Syphilis blitz
- HIV/syphilis task force (Navajo Nation project)
- Utilize elders to educate community
- Focus on sense of community that starts with family and tribe

## Socio-political Factors

### Barriers

#### IHS Lack of Knowledge of CARE Act

#### Lack of Communication Between IHS, HRSA, other Federal agencies and NAs/ Tribal Governments

#### Lack of Understanding of Native Health Care System

- Among providers and general population
- Perception that health care is taken care of for NAs (through IHS)

### Facilitators

- Enhance working relationship between IHS and HRSA through more frequent meetings
- Coordinated efforts between IHS, tribes, urban populations, and studies
- Need point person to coordinate these programs and this coordination has to be done with NA participation (e.g., food example, \$2 is allocated through CARE Act, had to get it increased to \$8 - major fight)
- Educate grantees, states and service providers about the mechanisms in place to address NA health care (tribal compacting, urban health clinics, IHS, etc.)
- Establish a HRSA Tribal advisory board

## Socio-political Factors (continued)

Barriers	Facilitators
<p><b>Tribal Recognition</b></p> <ul style="list-style-type: none"> <li>• Tribes not recognized by state or Federal government</li> <li>• Individuals who are not enrolled as members of a recognized tribe</li> </ul> <p><b>No Accountability of IHS for HIV/AIDS Funding</b></p> <ul style="list-style-type: none"> <li>• IHS criteria for services impacts access to care</li> <li>• Lack of monitoring of IHS HIV funds</li> </ul> <p><b>Bureaucratic Federal Health Care Systems</b></p> <ul style="list-style-type: none"> <li>• No Native American advocates within</li> </ul>	<ul style="list-style-type: none"> <li>• Coordinate communication and efforts between IHS and tribes to clarify eligibility criteria</li> <li>• Strengthen IHS HIV program - increase funding</li> <li>• Require IHS to track expenditures of HIV program funds (accountability)</li> <li>• Increase NA involvement in Federal Health</li> <li>• HRSA should create a NA ombudsman to bring about change</li> </ul>

## Care Services System

Barriers	Facilitators
<p><b>Lack of Cultural Competence</b></p> <ul style="list-style-type: none"> <li>• Lack of culturally competent care (need people who understand the community and make sure care is sensitive)</li> <li>• Lack of services for sub-populations and different NA tribes (tribal, state, Federal) (programs designed for NAs in general may not meet the needs of subpopulations e.g., Alaskan natives)</li> <li>• Lack of culturally competent services to meet needs of NAs by age, sexual orientation, gender identity and sex (women, gay men , youth, elders)</li> </ul>	<ul style="list-style-type: none"> <li>• Incorporate Native American traditions in outreach, education, and care</li> <li>• Native American case managers</li> <li>• Peer educators</li> <li>• Peer advocacy, mentoring</li> <li>• Elders to educate others on HIV</li> <li>• Cultural competency training for providers regarding integration of holistic views of health and wellness, Native American traditional medicines and healing practices into care delivery</li> </ul>

## Care Services System (continued)

Barriers	Facilitators
<p><b>Lack of Cultural Competence (continued)</b></p> <ul style="list-style-type: none"> <li>• Focus on completion of CARE Act paper work rather than on client needs during intake process reflects lack of cultural competence</li> </ul>	<ul style="list-style-type: none"> <li>• Train providers to conduct culturally competent intakes that are relevant to Native community and focus on the individual's needs rather than completion of paperwork (intake process needs to be welcoming and engaging, not focusing on paper work. It can take days or weeks to get people to open up and share)</li> <li>• Streamline documentation requirements for applications for CARE Act services</li> </ul>
<p><b>Limited Case Management Services</b></p> <ul style="list-style-type: none"> <li>• Inadequate funding</li> <li>• Focus is on the medical model, needs to also include social service side</li> <li>• ASOs tend not to work with tribal service providers to meet social service needs</li> </ul>	<ul style="list-style-type: none"> <li>• Increase Native American case management programs</li> <li>• Increase funding to support Native American case management programs</li> <li>• Education/training of non-Native American case managers regarding culturally appropriate services for NA and their care/support needs</li> </ul>
<p><b>CARE Act Program Policies</b></p> <ul style="list-style-type: none"> <li>• Approval of transportation</li> <li>• Turning clients away if they are late for specialty appointments</li> <li>• Clients not able to see doctors for six months if they miss appointments</li> </ul>	<ul style="list-style-type: none"> <li>• Provider education around the challenges of accessing services in rural areas</li> <li>• Flexible re-scheduling policies</li> </ul>
<p><b>Lack of Trained Medical/Social Service Providers</b></p> <ul style="list-style-type: none"> <li>• Trained NA providers within IHS, tribal and urban programs (bringing care back to ourselves)</li> </ul>	<ul style="list-style-type: none"> <li>• Increase capacity of Native Americans to provide care and support services by providing education/training within the community</li> <li>• Increase provider education</li> </ul>

## Care Services System (continued)

Barriers	Facilitators
<ul style="list-style-type: none"> <li>• Lack of Natives working with Natives</li> <li>• People who do not know what they are doing</li> <li>• Lack of HIV education (basic AIDS 101)</li> <li>• High turnover rates of providers</li> </ul>	<ul style="list-style-type: none"> <li>• Increase number of trained Native American case managers</li> <li>• Utilize Native American peers and elders to provide education</li> <li>• Increase pool of trained Native American providers</li> <li>• Lower caseloads</li> </ul>
<p><b>Lack of HIV Services for Incarcerated Populations</b></p>	<ul style="list-style-type: none"> <li>• Pre and post release HIV prevention and care services especially for incarcerated and recently released Native American men</li> </ul>
<p><b>Lack of Collaboration</b></p> <ul style="list-style-type: none"> <li>• Duplication of services</li> <li>• No MOA or linkage agreements</li> <li>• Issues of territory between programs (creates distrust)</li> </ul>	<ul style="list-style-type: none"> <li>• Promote Inter-tribal/agency collaboration</li> <li>• Different government agencies should mandate local agencies to work together</li> <li>• Coordinate efforts between IHS, states, tribes and urban health programs</li> <li>• More linkages between non-Native American and Native American organizations</li> <li>• Linkage agreements that work (not just on paper)--need to know that people who are getting the funds are actually providing the services</li> <li>• Collaboration for Native American issues through the state, CBOs, Native service organizations</li> </ul>

## Care Services System (continued)

Barriers	Facilitators
<p><b>Lack of Integrated and Comprehensive Care Services</b></p>	<ul style="list-style-type: none"> <li>• Fund models of integrated services for NAs</li> <li>• Integrate HIV, substance abuse and mental health services, and address other needs</li> <li>• Develop holistic service models that integrate spirituality, traditional medicines and healing practices</li> <li>• Address historical traumas that underline mental health, alcoholism, substance abuse, domestic violence and related problems</li> </ul>
<p><b>Lack of Data and Needs Assessment Tailored to Specific NA Tribal Groups and Sub-populations</b></p> <ul style="list-style-type: none"> <li>• Native American needs in one community are not necessarily generalizable to all NAs</li> <li>• Native Americans east of the Mississippi are not considered when programs/funding - focus is on Native Americans in West</li> </ul>	<ul style="list-style-type: none"> <li>• Dispelling Native American myths (goes with "labeling")-- something that fits with one tribe might not work with another.</li> <li>• Conduct tailored needs assessments</li> <li>• Use data on specific Native American tribes or sub-populations to allocate funding and design programs to meet their unique needs.</li> <li>• Address needs and gaps in services for Native American populations East of the Mississippi</li> </ul>
<p><b>Lack of Data to Support Needs</b></p> <ul style="list-style-type: none"> <li>• Funding decisions are made based on data</li> <li>• The data on Native Americans is based on national data which reflects low number of HIV/AIDS cases</li> <li>• Little funding is targeted to meet Native Americans' needs</li> </ul>	<ul style="list-style-type: none"> <li>• Use more localized data collection, surveys and needs assessments (data can tell us what is still needed)</li> <li>• Mentor Native Americans to develop data collection and research skills</li> </ul>

## Care Services System (continued)

Barriers	Facilitators
<p><b>Lack of Native American Services</b></p> <ul style="list-style-type: none"> <li>• No services and/or loss of services</li> <li>• Services developed through demonstration programs not sustained</li> </ul>	<ul style="list-style-type: none"> <li>• Develop planning grants for SPNS prior to the award of SPNS projects (everything has to be approved by Institutional Review Boards (IRBs), a one-year planning process to develop IRB system would make things more efficient)</li> <li>• Fund programs based on outcomes</li> <li>• Provide funding for Native American specific programs</li> </ul>
<p><b>Lack of Infrastructure to Sustain or Expand Services</b></p> <ul style="list-style-type: none"> <li>• Lack of education about service infrastructure for providers</li> <li>• Funding (needs exceed services)</li> </ul>	<ul style="list-style-type: none"> <li>• Hire good resource developers</li> <li>• Provide funding for infrastructure development</li> <li>• Fund Native American CBA services</li> <li>• Increase funding to programs (HRSA, state, tribal, etc.)</li> </ul>
<p><b>Distrust of Systems</b></p> <ul style="list-style-type: none"> <li>• No Voice</li> </ul>	<ul style="list-style-type: none"> <li>• Demonstrate commitment to Native American communities by providing continuity of funding for services (i.e. develop mechanisms to transition programs developed under SPNS to on-going RWCA funding streams)</li> <li>• Governmental agencies at local, state, and federal agencies should provide mechanisms for more Native American input into planning and decision-making on health care services</li> <li>• Increase Native Americans at local, state, and federal level in key positions related to planning and policy</li> </ul>

## Care Services System (continued)

Barriers	Facilitators
<b>Distrust of Systems (continued)</b>	<ul style="list-style-type: none"> <li>• Develop advisory groups, and engage Native American community representatives in planning for Native American community services</li> <li>• Increase Native American participation on RWCA consortia and where applicable, local Title II planning councils</li> </ul>

## Discussion

Many of the issues identified as barriers to access in this section were previously identified and discussed in the section on community challenges. This discussion will therefore highlight key issues not previously discussed.

### Rural Areas and Transportation

The participants identified a number of barriers to care related to the location of programs and services. There is a lack of programs in rural areas and clients experience isolation. The programs available to urban areas are not appropriate for Native Americans living on reservations or in rural areas. Transportation is a major issue as discussed in the community challenges section. It can take two to three hours or more for a person living in a rural area to reach a care site for services. Responses to these problems include recommendations to increase the supply of medical providers in rural areas, increase use of telemedicine, mobile care providers, and provide funding to airlift clients, especially in remote Alaskan villages to service appointments in urban areas.

### Poverty, Co-morbidities and Other Social Problems

As previously discussed, poverty and high indices of other health social problems create significant barriers to access to HIV/AIDS care for Native Americans. Culturally appropriate, holistic and integrated approaches to service delivery are needed to address the complexity of issues faced by Native Americans living with HIV/AIDS.

### Socio-cultural Barriers

Socio-cultural barriers include language diversity, the complexity of problems facing individual clients, sexism and racism/elitism. In regard

to racism, participants noted that external and internal racism impedes access to services. One of the major barriers related to access, particularly to IHS and tribal health services, has to do with the eligibility criteria for IHS services and enrollment in a federally recognized tribe. Tribes can run their own health services and establish eligibility criteria. Because of limited funding, some tribes are limiting the provision of health services only to enrolled members of their tribe. Depending on the enrollment criteria set by the tribe, Native Americans who do not meet the ancestry standard (i.e. full-blood, 1/2-blood, 1/4/-blood) may not be eligible for services. IHS' criteria require maintenance of residency on or near a reservation or rural area. This leaves many urban Native Americans in limbo. One participant who does not meet the enrollment criteria of his tribe said "That is the only thing I like about the CARE Act - Native American people don't have to produce a card to get CARE Act services."

In response to barriers related to community perception of HIV/AIDS, lack of awareness, and apathy, participants recommended peer education, integration of HIV with STD prevention, and increasing the visibility of Native Americans living with HIV/AIDS in the media. One participant commented that Native Americans do not see people like themselves on TV or in HIV education materials and, therefore, do not identify HIV as an issue that affects them directly.

### **Socio-political Factors**

A number of barriers were identified that are connected to the relationships and communications of the IHS with other federal agencies such as HRSA and with tribal governments. Participants noted that IHS lacks knowledge about the CARE Act and the interrelationship of CARE Act services to its own. There is also a lack of understanding of the Native health care system by providers, states, and some federal entities. There is, for example, a misconception that the Native health care system provides universal health services to all Native Americans. As noted previously, tribal recognition is another issue. There are many tribes that do not have federal recognition and, therefore, are ineligible to receive IHS services or funding. Individuals who are not enrolled as members of federally recognized tribes are also ineligible for these services.

Some CARE Act providers mistakenly believe that Native Americans are ineligible for their services. HRSA issued HAB: Policy Notice 00-01 *The Use of Ryan White CARE Funds Act Funds for American Indians and for Alaska Natives and Indian Health Service Programs*<sup>37</sup> to clarify these issues. However, participants stated there is still misunderstanding.

The participants also noted that many health care officials and providers do not understand that Native American relations with the Federal government are different than with other people of color. Native American tribes are sovereign nations (government to government relationship). Native Americans are often included in initiatives for communities of color only as an afterthought. HRSA needs to deal with Native American tribes in the same way they deal with states. The participants recommended a series of measures to address these problems, including enhancing communication between HRSA/HAB and IHS; coordinated efforts between IHS, tribes and urban health programs to address gaps in services; education of CARE Act grantees on the Native health care delivery system and on HAB's policy; and that HAB establish a tribal advisory board. Participants also recommended that HRSA finalize a tribal consultation policy as CDC has done in response to a presidential memorandum issued in April 1994.<sup>38</sup> Another option proposed was a subject matter experts group to assist HRSA/HAB on Native American issues. Participants noted that generally, Native Americans are left out of the policy discussions at the federal level regarding people of color.

Other issues raised have to do with the lack of accountability of IHS for HIV funding, and lack of Native Americans in decision-making positions within other federal health agencies such as HRSA/HAB. Participants stressed the need for IHS to monitor its expenditures on HIV services. They also recommended that HRSA create a Native American ombudsperson position to address problems related to access to health services by Native Americans, to serve as an internal advocate for changes to improve access. Another participant suggested that HRSA work with CDC on joint funding initiatives for underserved Native American areas such as Alaska. More collaboration would streamline the funding process and eliminate some competition.

### **Care Services System Barriers**

The participants noted a number of barriers to care within the HIV care services delivery system including: lack of cultural competence, limited case management services, lack of trained medical and social services providers, lack of integrated and comprehensive services, lack of collaboration among providers, and lack of services for incarcerated and recently released individuals.

### **Lack of Cultural Competence**

The participants emphasized the importance of cultural competence in the delivery of services to the diverse sub-populations of Native Americans affected by HIV/AIDS. They affirmed that the diversity of

the Native American population in terms of tribal affiliations, cultures, languages spoken, spiritual beliefs, as well as gender, sexual orientation and gender identity, age, urban, rural or reservation residence, educational attainment, economic status, and co-morbidities demands tailored services. They recommended that service provider and grantees provide cultural competency training to organizations and staff serving Native American populations. Such training should include information and skills building training on Native American cultural values and health beliefs, the role of elders in education and community life, traditional medicine and healing, culturally competent intake procedures and assessments, and spirituality. They also stressed the importance of integrating culturally competent approaches into outreach, education, and care services.

### **Lack of Native American Service Providers**

While the participants recognized that Native Americans may be served by non-Natives, they stressed the importance of increasing the pool of trained Native American, case managers, peer educators, mentors and care providers. One participant noted there are very few people doing HIV work in Native communities in Alaska. There are barriers at so many levels. The people don't want to hear the message from either outsiders or insiders. There is a need to have more providers to "normalize" HIV in the community. They, therefore, recommended initiatives to support the education and training of Native Americans to take on HIV related service delivery roles such as case managers, outreach workers, treatment educators and medical providers.

The participants also identified CARE Act program policies and documentation/paperwork requirements as barriers to engagement of Native American clients in services. They noted that many service providers focus more of their time and attention on completing paperwork rather than on developing meaningful and culturally appropriate relationships with their clients. They recommended that CARE Act program application documentation requirements be streamlined.

Other participants recommended that education and training opportunities for Native Americans be designed within a Native cultural framework rather than based on Western learning formats. Some suggested government funding of a national Pow Wow on HIV and funding to bring together tribal nation leaders to discuss HIV. These would probably be cost-effective ways to bring together Native Americans for educational and planning purposes. HIV issues could be addressed by integrating Native cultural elements and communication

styles such as music and story telling. They stressed that the approaches that have been successful with other communities of colors do not necessarily work for the Native American communities.

### **Breaches in Confidentiality**

Breaches in confidentiality have been noted as a serious deterrent to utilization of HIV testing and care services by Native Americans. The participants recommended that resources be made available for provider training on culturally sensitive approaches to assure client confidentiality.

### **Limitations of Data Collection and Needs Assessments**

The limitations of data collection on Native American populations was repeatedly cited as a barrier to planning and delivery of effective care services targeted to Native American sub-groups. One participant commented on the ineffectiveness of data collection methods among Native populations and stated that federal government needs to find different ways to get feedback from tribal entities that are not based on Western methods that rely on linear statistical modes. Data collection and research on Native American health issues needs to be based on traditional Native ways.

Another participant noted that the actual number of Native Americans affected is probably a lot higher than the official statistics indicate. For example, 54 percent of the patients receiving HIV services in Navajo Nation were diagnosed with AIDS when they presented for services. This indicates they are testing late and therefore entering care late. Retention in care is sporadic. For Navajo people, this varies from state to state. Retention is good in New Mexico, not as good in Arizona. Care received can depend on where you live. Another participant noted that client mobility affects data collection and resource allocation. For example, clients travel to receive services from rural to urban areas and many times cross state lines. Some clients go to Phoenix for primary care and then get their case management services on the reservation. There needs to be a system for counting these clients because with multiple providers involved, one of the providers may not be able to get paid for the services provided. Funding is based on client case counts. This issue needs to be addressed.

The participants recommended a variety of strategies to address these issues including more localized data collection (population-based surveys and needs assessments), conducting needs assessments tailored to specific Native American tribes and cultural groups, and targeting specific data collection and community based needs assessments to the tribes and Native American communities, East of the Mississippi River.

They noted that most of the funding is being directed to programs in the Western areas of the country where the largest Native American population concentrations are found. However, there are also many unmet service needs among Native populations in the Eastern region. Finally, the participants noted that Native American service providers need training, technical assistance, and mentoring on data collection and the use of data for program planning, monitoring, and evaluation.

### **Lack of Support for Native Programs**

The lack of support for Native American operated service programs was underscored as a major impediment to access to care by Native Americans living with HIV/AIDS. The participants noted that due to the limited numbers of Native Americans affected by HIV/AIDS, when compared to other ethnic and racial minority groups, resources to support Native American programs are limited. However, the complexity of service needs and diversity of Native American populations places additional demands on program and are more resource intensive. For example, the ratio of clients per case manager is an issue. The nature of case management services in rural areas is very different from those in urban settings. In many rural areas clients do not have telephones, and case managers have to drive long distances to see their clients. Caseloads in rural areas can be smaller but the services provided are much more time and labor intensive. Another participant noted that in Alaska, the quality of care depends on whether you live in an urban or in a rural area. Gender is also a factor. Women are better than men in seeking care. There are a large number of Alaska Native men in jail and the Department of Corrections (DOC) is not particularly good at testing for HIV. In addition, tribes don't want to provide HIV testing since they cannot provide the care. The lack of support for Native American service programs also reinforces Native Americans' historical distrust of government. Native American programs are often faced with budget shortfalls that result in cuts backs in or elimination of services. This lack of continuity of services is viewed as a breach of faith, and leads to further distrust of the system.



# Endnotes

<sup>1</sup> U.S. Census Bureau, 2000 Census of Population and Housing, *Summary Population and Housing Characteristics*, PHC-1-1, United States Washington, DC, 2002, pp. 4-6.

<sup>2</sup> Centers for Disease Control and Prevention (CDC), *HIV/AIDS Surveillance Report* 2002; 14: [p.18].

<sup>3</sup> Smedley BD, Stith AY and Nelson AR, Editors, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Institute of Medicine of the National Academies, The National Academies Press, Washington, DC, 2003.

<http://books.nap.edu/books/030908265X/html/R1.html#pagetop> p. 61.

<sup>4</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB), *Fact Sheet: Ryan White Care Act - Purpose of the CARE Act*: <http://hab.hrsa.gov/history/purpose.htm>.

<sup>5</sup> Summers T, Alagiri P, Kates J, *Federal HIV/AIDS Spending: A Budget Chartbook Fiscal Year 2002*, the Henry J. Kaiser Family Foundation, Fifth Edition, September 2003, p. 5.

<sup>6</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB), *Ryan White CARE Act 2001 Data Report for Title I, Title II*, <http://hab.hrsa.gov/reports/saar2001/saar2001report.htm>; *Ryan White CARE Act Title III 2001 Data Report* <http://hab.hrsa.gov/reports/titleiii2001/2001t3report.htm>; *2001 Ryan White CARE Act Title IV* <http://hab.hrsa.gov/reports/TitleIV2001/>.

<sup>7</sup> CDC, *HIV/AIDS Surveillance Report* 2002; 14: [12].

<sup>8</sup> CDC, *Ibid*, pp. A3 and A5.

<sup>9</sup> *Ibid*, pp. A2-A5.

<sup>10</sup> *Ibid*,

<sup>11</sup> CDC, *HIV/AIDS Among American Indians and Alaskan Natives -- United States, 1981-1997*, MMWR, March 6, 1998/ 47(08);154-160.

<sup>12</sup> CDC, *Ibid*.

<sup>13</sup> CDC, *Characteristics of persons living with AIDS and HIV, 2001.HIV/AIDS Surveillance Supplemental Report*, 2003; 9(No. 2): Table 7 <http://www.cdc.gov/hiv/stats/hasrsupp92/table7.htm>.

<sup>14</sup> CDC, *Surveillance for Health Behaviors of American Indians and Alaska Natives-Findings from the Behavioral Risk Factor Surveillance System, 1997-2000*, MMWR August 1, 2003/52 (SS07);1-13.

<sup>15</sup> HRSA/HAB, *Programs: American Indians, Alaska Natives, & HIV/AIDS*, Fact Sheet, <http://hab.hrsa.gov/programs/factsheets/navfact.htm>.

<sup>16</sup> HRSA/HAB, *Ryan White CARE Act 2001 Data Report for Title I, Title II*, <http://hab.hrsa.gov/reports/saar2001/saar2001report.htm>; *Ryan White CARE Act Title III 2001 Data Report* <http://hab.hrsa.gov/reports/titleiii2001/2001t3report.htm>; *2001 Ryan White CARE Act Title IV* <http://hab.hrsa.gov/reports/TitleIV2001/>.

- <sup>17</sup> HRSA/HAB, Fact Sheet, <http://hab.hrsa.gov/programs/factsheets/navfact.htm>.
- <sup>18</sup> Substance Abuse and Mental Health Services Administration (SAMHSA), Fact Sheet, Native Americans, Culture Race, and Ethnicity: A Supplement to Mental Health: A report of the Surgeon General, found at <http://www.surgeongeneral.gov/library/mentalhealth/cre/fact4.asp>.
- <sup>19</sup> The term, "Native American," came into usage in the 1960s to denote the groups served by the Bureau of Indian Affairs: American Indians and Alaska Natives (Indians, Eskimos and Aleuts of Alaska). Although there are differences in preference for the use of this designation among various sub-populations of American Indians and Alaska Natives it will be used in the text to refer to these groups in aggregate unless otherwise specified.
- <sup>20</sup> Ogunwole SU, *The American Indian and Alaska Native Population: 2000*, Census Brief C2KBR/01-15, US Census Bureau, February 2002, pp. 1-5.
- <sup>21</sup> Foquera R, *Urban Indian Health*, Issue Brief, The Henry J. Kaiser Family Foundation, November 2001, Appendix 1.
- <sup>22</sup> Ibid., p.6.
- <sup>23</sup> Federal Register: July 12, 2002 (Volume 67, Number 134), from the Federal Register Online via GPO Access [[wais.access.gpo.gov](http://www.access.gpo.gov)]
- <sup>24</sup> Ibid., p.8.
- <sup>25</sup> Ibid, p. 10. The numbers include the tribal grouping reported alone, or in any combination with another race or tribal group.
- <sup>26</sup> Ibid, p. 9.
- <sup>27</sup> Bauman KJ, and Graf NL, *Educational Attainment: 2000*, Census 2000 Brief, C2KBR-24, US Census Bureau, August 2003, pp. 5-6.
- <sup>28</sup> Bishaw A, and Iceland J, *Poverty: 1999*, Census Brief 2000, C2KBR-19, US Census Bureau, May 2003, pp. 5-6.
- <sup>29</sup> The Henry J. Kaiser Family Foundation, *American Indians and Alaska Natives: Health Coverage and Access to Care*, Fact Sheet February 2004, p. 1.
- <sup>30</sup> CDC, *Health Status of American Indians Compared with Other Racial/Ethnic Minority Populations ---Selected States, 2001-2002*, Morbidity and Mortality Weekly Report, November 28, 2003, /52 (47); 1148-1152. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5247a3.htm>.
- <sup>31</sup> SAMHSA, op cit.
- <sup>32</sup> Forquera, Ibid, p. 8.
- <sup>33</sup> The Henry J. Kaiser Family Foundation, Fact Sheet: *American Indians and Alaska Natives: Health Coverage and Access to Care*, February 2004, p. 1.
- <sup>34</sup> Zuckerman S, Haley J, Roubideaux Y, and Lillie-Blanton M, Health Service Access, Use, and Insurance Coverage Among American Indians/Alaska Natives and Whites: What Role Does the Indian Health Service Play?, *American Journal of Public Health*, January 2004, Vol. 94, No. 1, 53-59.
- <sup>35</sup> Oropeza L, Clinician's Guide, *Working with Native Americans Living with HIV*, National Native American AIDS Prevention Center (NNAAPC), Oakland, CA, p. 4.

<sup>36</sup> Shelton BL, *Legal and Historical Roots of Health Care for American Indians and Alaska Natives in the United States*, Issue Brief, The Henry J. Kaiser Family Foundation, February 2004, p.3.

<sup>37</sup> "The AIs/ANs hold triple citizenship. Federally-recognized AIs/ANs are documented members of tribal entities officially recognized by the U.S. Bureau of Indian Affairs, as well as citizens of the United States. In addition, they are citizens of an individual State. It is this multi-citizenship that enables them to receive services under the Ryan White CARE Act. Thus, AIs/ANs can claim CARE Act services for which they are eligible where they choose, regardless of the availability of services that may also be available to them (e.g., through Indian Health Service, tribal, or urban Indian health programs and services). This policy ensures that AIs/ANs have direct and unfettered access to CARE Act programs. In addition, this policy clarifies the circumstances under which the IHS may and may not receive funds under the Ryan White CARE Act."

<sup>38</sup> Memorandum to the Heads of Executive Departments and Agencies from President William J. Clinton, April 29, 1994, states: "Each executive department and agency shall consult, to the greatest extent permitted by law, with tribal governments prior to taking actions that affect federally recognized tribal governments. All such consultations are to be open and candid so that all interested parties may evaluate for themselves the potential impact of relevant proposals."