

# American Indian and Alaska Native Mental Health Research

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# ALCOHOL PROBLEMS IN ALASKA NATIVES: LESSONS FROM THE INUIT

J. Paul Seale, M.D., Sylvia Shellenberger, Ph.D., and John Spence, M.D.

Abstract: In this Alaska Native study, cultural "insiders" analyzed problems associated with increased alcohol availability, factors which have reduced alcohol-related problems, and ideas for improving treatment in an Inuit community. Participants described frequent bingeing, blackouts, family violence, suicide, loss of child custody, and feelings of intergenerational grief. Helpful existing treatment approaches include alcohol ordinances, inpatient treatment programs, twelve-step groups, and religious involvement. Participants urged the development of family treatment approaches which integrate Inuit customs and values.

#### Introduction

Alcohol abuse and dependence are common among Alaska Natives and are associated with high rates of violence and health problems (Brems, 1996; Segal, 1991, 1999; Segal & Hesselbrock, 1997; Shore, Manson, & Buchwald, 2002). While recent findings from the American Indian Service Utilization, Psychiatric Epidemiology, Risk and Protective Factors Project (Al-SUPERPFP) study have clearly documented the high prevalence of alcohol use disorders in American Indians (Spicer et al., 2003; Beals et al., 2005), there has been no major epidemiologic study documenting their prevalence in Alaska Natives as a whole or in any of the five major Alaska Native cultural groups (Athabaskan, Yup'ik, Inupiaq, Tlingit-Haida, and Aleut). Existing data do indicate, however, that Alaska Native alcohol-related death rates are almost nine times the national average, and approximately 7% of all Alaska Native deaths are

alcohol related (U.S. Department of Health and Human Services, Indian Health Service, 2001). Three landmark studies between 1989 and 1994 the Alaska Federation of Natives (1989) study, the Pulitzer Prize-winning series "A People in Peril" by the Anchorage Daily News (1989), and a report from the Alaska Natives Commission (1994)—confirmed that problem drinking is "epidemic" among Alaska Natives and identified alcohol abuse as their number one health problem. A 1998 Alaska statewide telephone survey by the Gallup Organization (1998) found that 14.9% of American Indians and Alaska Natives were dependent on alcohol, and another 4.1% were alcohol abusers. Heavy drinking is associated with suicidal behavior, suicide and deaths from unintentional injury (Kettl & Bixler, 1993; Marshall & Soule, 1998; Borowsky, Resnick, Ireland, & Blum, 1999). Unintentional injury rates are more than three times higher than the overall U.S. population, while suicide rates are more than four times higher (U.S. Department of Health and Human Services, Indian Health Service, 2001). Suicide is a particularly critical problem among young male Alaska Natives, who are 14-40 times more likely to commit suicide than other U.S. males in the same age group (Marshall & Soule, 1998; Center for Substance Abuse Prevention, 2002). Alcohol use is also linked to homicide, family violence, and fetal alcohol syndrome. Binge drinking and abuse of inhalants and marijuana is common, especially in male adolescents and younger adults (Zebrowski & Gregory, 1996; Stillner, Kraus, Luekefeld & Hardenbergh, 1999; Miller et al., 2002; Denny, Holtzman & Cobb. 2003).

Numerous American authors have emphasized the need for a culturally appropriate understanding of identified problems of American Indians and Alaska Natives because of the complexities and varying influences related to alcohol problems (Spicer et al., 2003), and the history of alcohol researchers who have alienated communities by excluding Native peoples from participation in the design, conduct and interpretation of results. (Mohatt, Hazel, et al., 2004). Research methods and interventions need to be designed with collaboration from Native people using constructs and procedures that make sense to community members, avoid repeating historical trauma, are respectful of their privacy and culture, build on their historical traditions of healing, and identify their areas of strength and resiliency (Mills, 2003; Mohatt, Hazel, et al., 2004; Whitbeck, Adams, Hoyt, & Chen, 2004). Furthermore, researchers have stressed the importance of avoiding implications that may be interpreted as beliefs that the community lacks the capability to define and resolve its own problems (Fisher & Ball, 2003). Towards this end, opinions, suggestions, and participation from Alaska Native

leaders were sought at each step of the research process, during study development, data collection, data analysis, manuscript preparation, and revision. Leaders of the community who had participated in the planning for the project recruited the focus group participants. In terms of methods for data collection, focus groups and individual interviews were chosen as principal means because these methods fit with the cultural tradition of story-telling. Focus groups have previously been found useful in conducting cross-cultural research and identifying cultural knowledge (Hughes & DuMont, 1993), and have been used in other studies of Alaska Natives (Hazel & Mohatt, 2001). In the focus groups and individual interviews, questions were designed to first build trust with the focus group leaders and to encourage opportunities for telling stories related to the questions asked. Sufficient time was allocated for silent reflection and personal interaction.

Researchers have also emphasized the need for culturallygrounded interventions among American Indians and Alaska Natives. Inupiat culture teaches that a sense of well-being (ahregah) derives from being in balance with the environment. The air, wind, and water are believed to have healing powers. Likewise in social activities, family, church, and friends create an environment where one's own problems are absorbed through the contagious power of ahregah (Reimer, 1999). In works by Mohatt and Whitbeck and their colleagues, researchers have sought to integrate traditional cultural concepts into substance abuse prevention and treatment efforts (Mohatt, Rasmus, et al., 2004; Mohatt, Hazel, et al., 2004; Whitbeck, Chen, Hoyt, & Adams, 2004; Whitbeck, Adams, et al., 2004). The authors attempted to follow this research model of maintaining a focus on strengths and resilience, and integrating traditional cultural concepts into the search for solutions. This study is the second of three studies designed to explore how and why alcohol problems escalate among indigenous groups undergoing cultural transition, and how insights from individuals within the culture can contribute to solving those problems. This single-community study explored alcohol use among the Inupiat and Yup'ik peoples of northern Alaska, often referred to by others as Eskimo or Inuit (an anthropological term for the ethnic family that includes both the Inupiat and Yup'ik). Because these two groups have a relatively short history of exposure to beverage alcohol (Segal, 1983; Hild, 1981, 1987), and many of their communities remained isolated from large-scale daily cultural contact with Western culture until oil was discovered in 1968 (Segal, 1999), many people in these communities can describe firsthand the impact of increasing alcohol exposure during their lifetime. Our previous study among the Carib people of Venezuela suggested that insights from people within the culture can make an important contribution in guiding prevention and treatment efforts (Seale, Shellenberger, Rodriguez, Seale, & Alvarado, 2002).

This study sought to: (a) use a combination of quantitative and qualitative techniques to provide a culturally-relevant assessment of alcohol-related problems in an arctic Alaska Native community, (b) encourage Inupiat and Yup'ik individuals to identify factors contributing to alcohol-related problems in their culture and offer cultural insights that could guide future treatment interventions, and (c) to compare findings from the experiences of the Inupiat and Yup'ik with those of the Venezuelan Carib people.

## Method

# **Community description**

The study was conducted in September 2001 in an isolated coastal "hub village" above the Arctic Circle whose population is approximately 80% Alaska Native (primarily Inupiat, with some Yup'ik inhabitants). The surrounding borough includes eleven smaller villages ranging in population from 100 to 1,000. The town's government-sponsored health center provides inpatient and outpatient care and services the surrounding villages by teleconference and teleradiology. Common patient complaints include hypertension, diabetes, depression, respiratory infections, chest pain, and orthopedic complaints. Historically, the area was a trading center surrounded by numerous fish camps. Many inhabitants still participate in some subsistence activities such as fishing and hunting caribou, moose, and seal. Important cultural traditions involve preparation for the hunt, the successful taking of animals, cooking, and distribution of the meat (Reimer, 1999). Employment opportunities include the school district, health center, Alaska Native Corporation, government offices, and a nearby mine. Most inhabitants speak English, and some older individuals also speak Inupiag or Yup'ik. Contact with the outside world is possible via air and sea routes, and in winter by snowmobile or dogsled. Evidence of Western influence includes cars, trucks, snowmobiles, stores selling processed foods and manufactured goods, and cable television. Approximately 80% of homes have indoor plumbing. Alcoholic beverages can be imported, but "damp" laws prohibit alcohol sales within city limits. Alcohol is expensive, with one fifth of whiskey costing \$50. Bootlegging is reported to be common.

The study was approved by the Institutional Review Board of the Medical Center of Central Georgia, the medical director of the local hospital, and the head of the regional Alaska Native Corporation (ANC). Members of the ANC and administrative personnel at the Maniilaq Recovery Center and the Maniilaq Health Center assisted in the recruitment of subjects for this study. The head and administrative board of the regional ANC reviewed the contents of the article.

# **Qualitative methods**

Focus groups were conducted according to the method described by Varkevisser (1991): (a) groups of different age and gender composition were organized to gain a variety of perspectives; (b) target group size was 6-12 participants; (c) each 90-minute focus group discussion was directed by an experienced facilitator (SS or JPS); (d) the same set of questions was discussed in each group in order to limit inter-group variability; (e) all group members were encouraged to participate; and (f) the facilitator presented and verified his/her understanding of the group's key findings at the end of the discussion. The following questions, modified from two previous American Indian studies (Seale, Shellenberger, et al., 2002; Seale, Martinez-Leal, & Girton, 2003), were discussed: 1. How did your people drink before there was significant contact with outsiders? 2. How do people drink now? 3. Why do people drink? Take drugs? What motivates them to do so? 4. Is alcohol/drug use causing problems in individuals? If so, what are the problems? What problems have resulted from alcohol use? 5. How do family members and friends react when drinking problems or drug problems occur? 6. Is alcohol/drug use causing problems in the communities? If so, what are they? 7. Are there factors that have reduced consumption of alcohol in the communities? If so what are they? 8. What suggestions do you have for reducing problems related to alcohol/drug use here? Where recruitment was difficult and insufficient numbers of participants were available to conduct focus groups, structured interviews were conducted.

Participants were recruited by community leaders, church leaders, medical personnel, and alcohol treatment counselors. Participants were invited to participate in a study of past and current use of alcohol among the Alaska Native people in their area, designed

to identify drinking-related problems and help search for solutions. Signed consent was obtained. All participants were fluent in English, and no translators were utilized.

Tapes of focus group discussions and structured interviews were transcribed, reviewed, analyzed and coded by all three investigators two family physicians and a family psychologist. Analysis utilized a systematic iterative process of text interpretation and categorization in which the analysts identify meaningful referents and establish patterns of significance (Varkevisser, 1991). Two or three analysts reviewed each transcript together to identify meaningful units of information related to the research gueries. Findings were categorized into coding categories through consensus, before arriving at the thematic findings. Interpretive disagreements were resolved by debating supporting evidence. Coded answers to all questions by groups and interviewees were summarized on a spreadsheet. Statements were considered in terms of frequency, extensiveness, intensity and specificity to identify themes. Tables and visual summaries of data were prepared to communicate themes that emerged. As a measure of trustworthiness, the analysts reviewed the transcripts again in search of evidence contradictory to the findings. Community leaders read the findings to ensure the content had no possibility of traumatizing Alaska Natives. In addition, leaders who had participated in the focus groups reviewed the manuscripts and revisions for the purpose of assuring that focus group content was accurately reflected.

Four focus group discussions were conducted: (a) a men's inpatient treatment group (8 participants ages 22-43), (b) a women's inpatient treatment group (5 participants ages 23-45,) (c) the community's Alcohol Advisory Board (6 participants, all over age 50 and self-described as former heavy drinkers), and (d) a community women's group (6 participants, ages 24-60, 3 of whom described themselves as former heavy drinkers). While most participants lived in the town, numerous individuals had grown up in rural villages. Some individuals in inpatient treatment were from surrounding villages. Two individual structured interviews were conducted with male leaders in their 40s from the town's largest church. Neither was a current or former drinker. Two individuals who were originally recruited for a focus group discussion for young adults instead participated in structured interview (ages 20s to 30s); one was an active problem drinker awaiting inpatient treatment and the other did not disclose the drinking behavior.

## **Quantitative methods**

Alcohol use questionnaires were administered to a consecutive sample of patients in the town's only outpatient clinic in order to gather objective measures of alcohol use patterns and associated problems. The Alcohol Use Disorders Identification Test (AUDIT) was administered by a house officer and one of his supervising physicians to consecutive clinic patients over two weeks. Each patient seen by these physicians was asked to participate in an anonymous survey regarding drinking patterns in the region that would be used to assist local leaders in shaping alcohol programs in the community, and verbal consent was obtained. Emergency room visits were excluded, as they were felt to represent a skewed subset of the population at high risk for alcoholrelated problems. The AUDIT, a ten-question instrument validated by the World Health Organization in patients from six countries (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993), was chosen because it has demonstrated usefulness across a wide range of cultural settings (Rigmaiden, Pistorello, Johnson, Mar, & Veach, 1995; Schmidt, Barry, & Fleming, 1995; Gudmundsdottir & Tomasson, 1996; Holmila, 1995; Guevara-Arnal et al., 1995, Seale, Seale, Alvarado, Vogel, & Terry, 2002). AUDIT responses were used to calculate the prevalence of binge drinking (defined as consuming 6 or more drinks per occasion), problem drinking (defined by an AUDIT score of 8 or more), and various alcohol-related problems. Information from quantitative studies was integrated with results from focus group discussions and structured interviews.

# Results

# **Traditional patterns of drinking**

Focus group discussion and structured interview participants noted that alcoholic beverages were not indigenous to their culture, stating that alcohol was first introduced by whalers, fur traders, and visitors from Russia, who sporadically brought large quantities of distilled spirits into the communities. Men, women, and traders would drink freely until intoxicated, and traders would take sexual advantage of village women and economic advantage of men during trading. Intoxicated Native men would sometimes become violent with their wives. Alcohol use sometimes produced devastating consequences when hunting and fishing were neglected. One older woman related:

[One] summer they bought a whole bunch of alcohol... and the men stayed drunk. Spring is our time of gathering for the winter like hunting and fishing, but the men stayed drunk and we didn't stock food for the winter. And since there was TB and influenza with the diseases [the whalers] brought...we had no food for the winter...Eight out of the 10 villages were wiped out.

During the twentieth century, Western cultural contact increased as military posts, mines, canning facilities, and government agencies were established. By mid-century, alcohol could be purchased in many towns. Many people purchased alcoholic beverages or brewed alcohol from berries. Many Native men were exposed to heavy drinking through military service. Frequent heavy drinking became commonplace among men and women.

# **Current drinking patterns**

According to focus group discussion and structured interview participants, alcohol use and illegal drug use are now common among adults, adolescents, and pre-teens. Most focus group discussion participants began drinking at age 9-13. Marijuana use was reported to be prevalent. Some adolescents also engaged in inhalant abuse. Participants reported the recent death of a young girl from inhalant abuse.

AUDIT questionnaires provided additional information regarding alcohol use patterns. Questionnaires were completed by 21 male and 43 female patients (refusal rate 6%). The mean age was 37.2 for men and 33.8 for women. Analysis indicated 69.6% of men and 56.1% of women had consumed alcohol during the previous year. Whiskey was the most common beverage consumed, followed by beer. The mean AUDIT score was 4.9 for females and 10.3 for males. Answers to AUDIT questions are presented in Table 1. Binge drinking within the past year was reported by 60.9% of men and 36.6% of women, with 47.8% of men and 19.5% of women bingeing at least monthly.

Table 1
Responses to Alcohol Use Disorders Identification Test

		Score*	(0)	(1)	(2)	(3)	(4)
			Never	Monthly or less	2-4 times a month	2-3 times a week	4 or more times a week
1.	How often do you have a drink	Male (%)	30.4	26.1	26.1	8.7	8.7
	containing alcohol?	Female (%)	43.9	29.3	17.1	9.8	0
			1 or 2	3 or 4	5 or 6	7 to 9	10 or more
2.	How many drinks containing alcohol do you have on a typical	Male (%)	40.9	18.2	18.2	18.2	4.5
	day when you are drinking?	Female (%)	53.7	26.8	12.2	4.9	2.4
			Never	Less than monthly	Monthly	Weekly	Daily or almost daily
3.	How often do you have six or more	Male (%)	39.1	13.0	34.8	8.7	4.3
	drinks on one occasion?	Female (%)	63.5	17.1	12.2	4.9	2.4
4.	How often during the last year have you found that you were not able to stop	Male (%)	50.0	18.2	27.3	0.0	4.5
	drinking once you had started?	Female (%)	82.9	9.8	7.3	0.0	0.0
5.	How often during the last year have you failed to do what was normally expected	Male (%)	73.9	13.0	8.7	0.0	4.3
	from you because of drinking?	Female (%)	80.5	12.2	2.4	4.9	0.0
6.	How often during the last year have you needed a first drink in the morning to	Male (%)	82.6	8.7	0.0	0.0	8.7
	get yourself going after a heavy drinking session?	Female (%)	90.2	7.3	0.0	2.4	0.0
7.	How often during the last year have you had a feeling of	Male (%)	60.9	13.0	130	8.7	4.3
	guilt or remorse after drinking?	Female (%)	75.6	9.8	9.8	2.4	2.4
8.	How often during the last year have you been unable to remember what	Male (%)	56.5	21.7	8.7	13.0	0.0
before	happened the night before because you had been drinking?	Female (%)	82.9	9.8	4.9	2.4	0.0

10.

		No	Yes <sup>a</sup>	Yes <sup>b</sup>
Have you or someone else been injured as	Male (%)	60.9	30.4	8.7
a result of your drinking?	Female (%)	78.0	9.8	12.2
Has a relative or friend or a doctor or other health worker been concerned about your	Male (%)	47.8	26.1	26.1

0.0

9.8

Table 1, continued

drinking or

suggested you cut down?

Female (%)

# Why do people drink?

Respondents started drinking because of curiosity, wanting to have fun, or peer pressure. A young woman described progressing from recreational drinking to addictive drinking:

90.2

When you first start drinking, you start to have fun—it's fun! You are socializing, and then pretty soon, the more you drink...then you became dependent on it...so anything that triggers you to it from anger to pain to anything, you get dependent on it. You need to have that drink to feel good...

The most common reasons given for drinking were addiction, coping with problems, and forgetting painful experiences. A female respondent stated:

My dad, he was a pretty bad alcoholic and a drug addict, too...At the time of my conception, I think my mom and my dad were using, and my mom continued to drink with me when she was pregnant...I had a hard time learning in school...I had my first kid when I was 19, and I was in a very abusive relationship. I turned to alcohol to numb the pain.

<sup>\*</sup>n=23 males & 41 females

<sup>&</sup>lt;sup>a</sup> Not in the last year. <sup>b</sup> During the last year.

Individuals stated alcohol was easily accessible, and often family members taught them to drink. A young lady remarked:

I went to jail...at 12 years old for trying a sip of my sister's mix with Southern Comfort and 7-Up... She was always telling me to watch her... She asked me things like, "Watch me. Make sure nothing happens to me. Make sure nobody touches me or make sure nobody don't try to fight with me, and watch what I do just in case I don't remember"... When I was 12, she let me try it... and pretty soon, the cops came in and took us all to jail.

The stress, confusion, and depression caused by the dramatic cultural changes of the twentieth century were described as a major influence on alcohol consumption. The introduction of Western-style cash economy, military culture, police and court systems, religious practices, and educational institutions resulted in dramatic changes. Jobs became available for women. Many men were no longer their families' primary providers. Few men continued full-time subsistence activities. While some men worked, others were supported by their wives, often with severe emotional consequences. A female focus group volunteer noted:

Even our men, I think that's why they are so suicidal or use and abuse women, rape them because they got lost from the alcohol and their self worth....When alcohol came and grocery stores, they weren't really needed and money was really hard....They don't feel like they contribute and the women say, "I support you." So, they are ashamed and they turn to drinking. They have anger that makes them want to physically abuse or verbally or mentally abuse.

Parental authority was undermined as children were taught new ways of thinking by teachers and missionaries. Acts of violence committed while intoxicated resulted in feelings of profound shame and guilt. Older individuals described intergenerational grief from loss of contact with traditional ways that had brought a sense of identity, worth and self-esteem, and from witnessing the devastation occurring around them. A female focus group participant related:

A whole family drowned one Sunday... a total of nine people drowned from when they were drinking and going to town. And then on the same day, two people killed themselves...And my dad said..."I feel like my people are like the Jews." They never get over it, all the horror... They are still living in horror and shock and shame...

Younger individuals described feeling torn between desires to conform to their parents' wishes and wanting to achieve ideals they learned about on television and in school. A young female participant noted:

In the villages, I think it is more intense, too, with a loss of direction...They have the elders and the people... banging it into their heads..., "Live the old way, live the old way," whereas they are going to school...they don't know which way to go: to go to their old traditional ways, or to go to college...They get lost right in between.

Despair was common in both age groups, sometimes leading to attempted suicide by hanging, firearms, or walking out into the snow.

# **Alcohol-related problems**

Among patients completing AUDIT questionnaires, 47.8% of men and 24.4% of women met criteria for problem drinking. Common symptoms, experienced by about half of men, included being advised to cut back on their drinking, sometimes being unable to stop drinking, and experiencing memory blackouts. Common symptoms among women, seen in about one-fourth of patients, included guilt feelings after drinking, alcohol-related injury to themselves or others, blackouts, and failure to meet their responsibilities.

Focus group discussion participants described 44 problems related to drinking (see Table 2). Alcohol was reportedly associated with violent behavior, injury, and death. Deaths clustered in families where multiple members abused alcohol. A male inpatient related:

That was the way I was brought up, you know, watching my step-dad...and my mom drink. I lost all [four] of my brothers before they were 30 years old, two of them due

to alcohol...One died in a DWI accident this year, and the other one died in 1987. He froze to death....I lost two of my uncles to alcohol. One burned in a fire and one drowned. And I had an aunt that died from exposure.

Table 2
Focus Group Findings: Alcohol-related Problems

family violence victimization (violent crime) suicide death sexual abuse hunger loss of self esteem accidents lost in the snow/cold loss of stability isolation exposure fighting job problems loss of culture arrest loss of children not teaching subsistence customs to children economic problems family disintegration disorderly conduct loss of male identity poisoning from non-beverage alcohol quilt/shame illness/medical problems alcohol overdose romantic arguments/breakups premature babies marital infidelity child abuse/neglect overwork of children pregnancy/having children out of wedlock violent crimes keeping others awake sexual promiscuity drowning fetal alcohol effects murder verbal abuse of others threats of violence depression pass out diversion of government memory blackouts benefits received for children

Since the 1960's, alcohol-related suicide has been a major problem. A focus group discussion member involved in early suicide investigations described:

We gathered statistics...because we really didn't know what was causing it....We found out that we had 14 suicides in nine months only...and that set an alarm to everybody....They had nine in one village last June...It's a continuing problem, and it's mostly young males between the ages of...17 and 30.

A young man who had lost four friends to suicide became despondent as he related:

My best friend was struggling, I guess because his girlfriend was with someone else...He isn't much older than I am. I guess he couldn't cope with it and that's

why he did it...He never mentioned nothing...He just talked about being sad and depressed. I guess that was a sign...But he did end up killing himself.

Government institutions faced increasing numbers of alcoholrelated arrests, court proceedings, and medical problems. An Alcohol Advisory Board member related that 95% of the 1,400 individuals convicted of crime the previous year had committed alcohol-related offenses.

# **Family impact**

Interviewees described alcohol-related physical and sexual abuse, child neglect, hunger and marital conflict. A middle-aged man raised by his grandmother described:

My mother would drink with my uncles....She would never know that she hit me because she would have those blackouts, but that was because she would be drinking so much, you know, that she don't remember hitting me at all...I tried to run away, run to my grandparents' house, and...one day they happened to see the bruises on my arms and they pulled up my shirt... She said, "Well, where did these come from?"

Effects on nuclear families included separations, divorces, and loss of children who left home, were adopted out or became wards of the state. A female respondent described her childhood:

[My mother] was an alcoholic and a drug addict....I grew up... in a very violent home...My uncles and aunts used to drink and I would be scared to go to sleep...not knowing what I am going to wake up to...and everybody always drinking....I moved out of my mom's house when I was 16. I dropped out of high school and then I got adopted to my grandma.

Concerned family members responded to heavy drinking with arguments, rebukes, or threats. Children assumed adult responsibilities such as cooking, cleaning, or childcare. A female discussant related:

I had to babysit my mom's younger sister's kids. My mom would worry about those kids, and she would order me to go take care of them because the parents chose to

drink. ... She would say, "Get them out as soon as they go home," because they would start to fight and get abusive.

Some family members excused acts of drunkenness or counseled their spouses about quitting. Other family members tried pouring out the alcohol, physically restraining their intoxicated spouses, locking them out of the house, or calling the police. While many older participants described growing up in traditional Inupiat villages, some younger participants grew up in the town in families where few Inupiat customs were observed and life revolved around drinking. Anger was the most frequent emotion described by family members, followed by guilt. Respondents wondered whether the "damp" ordinances which prohibited local sales of alcohol but allowed importation and private consumption had actually increased family violence. After local bars closed, most alcohol consumption occurred in homes, and alcohol-related violence was often directed at family members.

# **Community impact**

Societal, educational and work consequences were identified as problems detrimental to the community as a result of drinking and drug use. Societal consequences included disorderly conduct, assaults and violent crimes, juvenile delinquency, sexual abuse, drug dealing, elder abuse/neglect, underage drinking, individuals in need of disability because of fetal alcohol syndrome (FAS), homelessness and imprisonment. Educational consequences emphasized the need for special education to address the needs of children afflicted by FAS. Work consequences included unreliable employees and the small labor pool resulting from failed drug testing by prospective employees.

# Factors associated with reduced consumption of alcohol in the communities

Focus group discussion participants and interviewees described 33 factors that have helped to reduce drinking and alcohol-related problems (see Table 3). Most frequently mentioned were liquor control ordinances, threats of legal action, inpatient alcohol treatment, Alcoholics Anonymous, religion and church involvement, elders' assistance in supporting sobriety, and personal willpower. Many felt that ordinances which restricted alcohol supply had reduced drunkenness, public intoxication, and alcohol-related violence. A male elder stated:

The hospital doctor made a statement. He said, "What's the emergency over at the hospital?" Well, all the bars and liquor stores were open. Somebody would get beat up...It was just a terrible situation here. But, when they stopped the drinking, it was peace, quiet peace. No more disturbances or killings from liquor.

# Table 3 Focus Group Findings: Factors Which Have Reduced Alcohol-related Problems

liquor ordinances (damp, drv) willpower/personal decision to guit Alcoholics Anonymous sobriety council/movement participation in formal alcohol treatment program legal action (jail, child custody proceedings) high cost of alcohol other spiritual/religious factors besides church spirit camps celebrations without alcohol advertising sobriety whole village involvement/community organization drug testing financial obligations influence of family

aging severe consequences of drinking revulsion spouse parenting responsibilities help from missionaries involuntary treatment talking to sober friend concurrent abstinence of both spouses cultural revival family involvement in treatment elders teaching parenting skills elders teaching anger management elders teaching how to resist cravings elder companionship elders teach taking legal action for family violence neighbors intervening

For numerous participants, recovery from problem drinking started with entering alcohol treatment to avoid jail sentences or the loss of child custody. Inpatient alcohol treatment and Alcoholics Anonymous helped many attain sobriety. Culturally-based interventions—integrating Inupiat values into formal alcohol treatment, recruiting elders to teach subsistence activities while also teaching tactics for managing anger and resisting craving, etc.—were helpful to others. A focus group participant described the creation of a statewide Sobriety Council:

We started a statewide program to push sobriety...It caught on and all over the state, sobriety would be in the weekend fun...What we said was for nondrinkers to get out of the closet and start pushing sobriety...[After a time] you would go to a party and it would be non-alcoholic drinks...So, that helped. It made it easier for nondrinkers and people who are recovering from drinking to exist in our community.

Traditional Christian religious practices such as church attendance, prayer, and faith in a Higher Power were important recovery factors for some. An elder described his aunt's experience:

[She] got addicted and she wanted to quit, but she couldn't. She heard or questioned the missionaries about there being a God. And one day when she heard about God, she got down on her knees and said, "God, I need help." All her desire for drinking just disappeared when that happened, and she became a very involved Christian after that.

# Suggestions for reducing alcohol-related/drug problems

Suggestions made by focus group members centered around developing effective treatment resources for those with severe drinking problems, developing alternative recreational activities for youth, utilizing spiritual resources, and advocating for necessary services. Two dominant themes regarding alcohol treatment emerged from discussions: creating family treatment programs and integrating more Inupiat customs and values into treatment efforts. Participants described the need for alcoholic spouses to obtain treatment together and for on-site childcare. Many expressed a desire for integrating Inupiat subsistence practices into treatment programs. Local plans for a therapeutic "spirit camp" modeled after another Alaska Native treatment center were described:

The Alcohol Advisory Board is trying to see if we could set up a camp away from [town] and away from the villages and make it a realistic program, where not only the victim or the one that is taking the alcohol and drugs but the whole family could go and start a healing process all together.

Participants elaborated on details they would like to see incorporated into treatment programs. For example, participants want to see flexibility for families to stay in rehabilitation programs for as long as they feel that they need to. Participants wanted to see support for people completing rehabilitation programs and returning to the community. One participant said:

We want programs put into place so that the people will start helping their own people get healed again.

Further, participants hoped to build a cadre of families geared to assisting other families as they return from treatment. They described the potential impact of a group of such strength:

It might take just a few families the first few years, but once it catches on, you know, I think you will lead a lot of others that are alcoholics.

Other culturally-based suggestions included establishing more sobriety clubs, using more Native peer counselors, and establishing tribal courts for handling minor drug and alcohol-related offenses. Two participants suggested creating integrated community plans that would involve local efforts at restitution and forgiveness after a legal offense as well as treatment for the offender's addiction problems. To develop such a plan, participants envisioned bringing together the elders' council, the tribal council, and the ministers. Young people suggested more alcohol-free recreational facilities. Two others mentioned the importance of church attendance and a deeper relationship with God.

Participants mentioned the need for advocacy at the state level for programs to benefit recovering community members, with statements such as:

We [young mothers] shouldn't act like nothing is wrong. It is important that we discuss these things...I hope that sometime soon we have the opportunity to travel to Anchorage to listen and discuss different concerns.

Finally, participants described the need to educate parents about values that reflect important legacies in their culture. In particular, self-discipline and discipline of children were described as major underpinnings of family structure. Participants were concerned that problems arose when community members became focused on money, began playing bingo, and used scarce resources for the game. Instead, they suggested,

We need to stop and take time, and take charge of our children and their children. The gift [from previous generations] was how they used discipline, which helped

them to keep control and give us a strong life. We need to discipline ourselves to be healthy and think about the legacy we will leave for the [next] generation. It's just to try to rekindle this age old way of discipline...There should be a lot of positive reinforcement and a lot of good talk.

# Discussion

This study provides unique insights into alcohol problems in this Alaska Native culture by allowing cultural "insiders" to describe their evolution over the past century. To our knowledge, it is the second study in the past two decades to attempt a quantitative analysis of problem drinking among Alaska Natives, although like the other study, it offers quantitative results which should be considered exploratory rather than definitive (Hazel & Mohatt, 2001). Binge drinking patterns are similar to those seen in other North and South American Indian groups (Weisner, Weibel-Orlando, & Long, 1984; Westermeyer & Baker, 1986; Robin, Long, Rasmussen, Albaugh, & Goldman, 1998; Seale, Seale, et al., 2002). While genetics may influence Native drinking patterns (Long et al., 1998; Wall, Garcia-Andrade, Thomasson, Cole, & Ehlers, 1996), cultural change also appears to be a significant contributor (Herman-Stahl, Spencer & Duncan, 2003). Evolving drinking patterns described by focus group discussion participants and interviewees parallel those observed among other North American Indian groups (Frank, Moore, & Ames, 2000) and a Venezuela Carib group which had a long history of binge drinking (Seale, Shellenberger, et al., 2002). In each case, individuals in cultures without clear cultural guidelines regarding alcohol use followed the example of heavy-drinking role models (soldiers, traders, etc.) with disastrous consequences. The apparent common denominator was not a lack of previous exposure to alcohol, but a lack of cultural guidelines for appropriate use of the "new beverages" and exposure to role models who were problem drinkers.

Our findings suggest differences in the motivations for drinking between the Inuit and the Caribs. Sadness, depression and despair were major reasons for drinking in Alaska, while Caribs reported drinking to celebrate and socialize. Our findings support those of other investigators who have found depression and intergenerational grief related to discrimination and historical loss to be strongly associated with alcohol problems among American Indians and Alaska Natives (Brave Heart & DeBruyn, 1998: Duran & Duran, 1995; Segal, 1999; Gray & Nye, 2001;

Whitbeck, McMorris, Hovt, Stubben, & LaFromboise, 2002; Whitbeck, Chen, et al., 2004). Focus group discussion participants frequently linked descriptions of problem drinking to the rapid, widespread disruption of indigenous culture and loss of male identity that has occurred in Alaska over the past century. Such changes have been less drastic in Venezuela, where most Carib families continue their traditional subsistence activities and men continue to function as leaders in their families. Of interest is the fact that the community-based spirit camp treatment approach advocated in focus group discussions emphasizes Inupiat cultural activities and encourages men to uphold leadership functions in their families. Other researchers have found a traditional cultural orientation to be protective against substance use disorders among American Indians and Alaska Natives (Herman-Stahl, et al., 2003; Mohatt, et al., 2004), and treatment approaches which engage participants in traditional practices have been shown in other tribes to protect against depressive symptoms (Whitbeck et al., 2002).

Differences in history and culture may also account for differing consequences of alcohol use between the Inuit and Venezuelan Caribs. Among the Inuit, alcohol-related suicide, family violence, and disruption of the nuclear family are frequent, while in Venezuela, hunger, economic problems and intentional injuries are the most common consequences (Seale, Seale, et al., 2002). Financial resources in Alaska from numerous government sources and Alaska Native mineral rights appear to have limited the economic consequences of problem drinking, thereby limiting alcohol-related hunger. Such resources are not available in Venezuela; thus, families face severe economic consequences if their primary breadwinner is alcohol-impaired. Intentional injury in the Caribs (Seale, Shellenberger, et al., 2002) and suicide in Alaska natives (Cameron, 1999; Kettl & Bixler, 1993) have escalated with increasing alcohol availability. These differences may be related to long-standing practices in each culture. Carib focus group discussion participants reported a link between drinking and fighting in their cultural festivals that predates commercial alcohol availability (Seale, Shellenberger, et al., 2002), while anthropologic studies report a long-standing practice of suicide in circumpolar cultures (Leighton & Hughes, 1955; Misfeldt & Senderovitz, 1989; Thorslund, 1990). Cultural upheaval and the struggle with whether to give up traditional customs may lead to disillusionment, depression and ultimately to suicide for some Alaska Natives (Kettl, 1998; Reimer, 1999; Reimer, 2002). These issues are much less prominent in Carib culture. Environmental factors may play a part as well. Some investigators have found associations between the Arctic's lack of daylight and long severe winters and the prevalence of depression and alcoholism (Haggarty et al., 2002; Booker & Hellekson, 1992; Sher, 2004). By contrast, Venezuela, where suicide is rare, has light year round and a moderate climate. These differences suggest that individual cultures manifest unique alcohol-related vulnerabilities, creating the need for individualized harm reduction strategies.

This study found higher current drinking rates among Inuit women than in recent studies of other American Indian and Alaska Native women (O'Connell, Novins, Beals, Spicer, & Al-SUPERPFP Team, 2005), and found evidence of severe family consequences associated with high rates of problem drinking among both men and women in Inuit families. Many focus group discussion participants described the emotional trauma of growing up in violent homes with addicted parents, aunts and uncles. In their review article on intimate partner violence in American Indian and Alaska Native communities, Oetzel and Duran (2004) emphasized the importance of addressing this issue with multilevel interventions tailored to the cultural context of the individual tribal group. Two other urgent priorities for future programs include exploring and addressing the factors contributing to high rates of problem drinking among women, and addressing the needs of the high-risk youth from alcoholic families, who are at increased risk for learning disorders, addiction, mental illness, risky sexual behavior and deviant behavior (Potthoff et al., 1998; Silverman & Schonberg, 2001).

Focus group discussions also highlighted the cultural diversity within the Inupiat culture and the diversity of their solutions to problem drinking. Some look to achieve sobriety in village spirit camps, while others attend Alcoholics Anonymous meetings and fly to Anchorage for inpatient treatment. We found, as did Hazel and Mohatt (2001), significant numbers of individuals who found a more formal Christian-based spirituality to be a support in staying sober, and others who saw the church as an obstacle to sobriety and pursued sobriety via Alaska Native spiritual traditions. Future programs face the challenge of providing services to clients from both traditional and non-traditional cultural and spiritual perspectives.

Finally, focus group discussions revealed the importance of employing a systems perspective, which takes into account issues related to family, community, environment, and culture, to view the problems and possible solutions to alcohol problems. Some interventions designed to decrease alcohol problems brought about unexpected results by impacting other aspects of the Inuit cultural system. For example, ordinances restricting alcohol supply have helped decrease murder rates,

accidental deaths, alcohol-induced birth defects, emergency injuries, alcohol-related police calls, and outpatient hospital visits (Albrecht, 1981; Landen et al., 1997; Berman, Hull, & May, 2000; Oversight hearing, 2000). However, some focus group discussion participants wondered whether family violence increased as alcohol-related violence moved from the streets into homes. In another example, one participant questioned whether public assistance programs, which have decreased hunger in some alcoholic families, may have prevented the severe economic consequences that often motivate substance abusers to seek treatment, thereby delaying treatment until their addiction reached a more advanced stage. Prevention and intervention approaches may assist in obviating unwanted or unexpected outcomes by anticipating and addressing the impact of changes in one aspect of the system on the system as a whole. Systems approaches may also allow growth and change in individuals and systems while at the same time maintaining the positive aspects of Alaska Native culture. For example, internal conflict, such as the stress experienced by adolescents when deciding whether to adhere to traditional ways or go to college, was linked by focus group discussion participants to depression and alcohol abuse. A systems-oriented solution may promote dialogue within families and communities to clarify choices and discover ways of maintaining old traditions while taking advantage of new opportunities.

# Limitations

Because substantial tribal differences exist in the prevalence of substance abuse disorders (May, 1996; Mitchell, Novins, & Holmes, 1999), findings of this study may not be generalizable to other Alaska Native groups. Nonetheless, this study provides important information on alcohol problems among the Inupiag and Yup'ik, thereby fulfilling the mandate of the U.S. Surgeon General to generate specific information regarding the mental health burden borne by American Indians and Alaska Natives (U.S. Department of Health and Human Services, 2001). While AUDIT questionnaire data obtained from a small sample of clinic patients is helpful in amplifying information obtained in focus group discussions, it has very limited statistical power and may not accurately reflect the prevalence of problem drinking. In addition, the AUDIT may have underestimated problem drinking rates because its twelve-month assessment period does not detect infrequent binge drinkers who have not consumed alcohol in the past year. Nonetheless, the prevalence of problem drinking seen is consistent with rates observed by Shore et al. (2002) among urban American Indian and Alaska Native primary care patients in Seattle and by Koss et al. (2003) in six other American Indian tribes. Information obtained in focus group discussions could be incomplete because of participants' hesitance to discuss sensitive issues with outside researchers. Nonetheless, the frequent discussion of sensitive topics such as suicide and family violence seem to indicate a relatively high level of openness among participants. Including large numbers of recovering persons in our focus group discussions may have provided an exaggerated view of the severity of alcohol-related problems in this population. Nonetheless, their viewpoints were consistent with those of other individuals who participated in focus group discussions and interviews.

# **Summary**

This rapidly-changing indigenous culture has responded to escalating alcohol-related problems with unique culturally-based approaches. Inupiat culture teaches that a sense of well-being (ahregah) derives from being in balance with the environment. Drinking and drug use and the concomitant social and family problems may detract from the balance. Participants in our focus group pointed to a way out of the cycle of problems, emphasizing the importance of building on the multigenerational legacies of their culture. Legacies they named included promoting discipline of self and children, teaching subsistence traditions and allowing family, church, friends, and communities to participate in healing of personal and family problems.

Inupiat leaders should be integrally involved in planning, implementing and evaluating culture-based treatment programs. Family treatment, depression and suicide prevention, services for high-risk youth, and research on female alcoholism are high priorities for future efforts. Successful grassroots projects (Noe, Fleming, & Manson, 2003) can serve as models for addressing problems of substance abuse in Alaska Native communities.

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# VIOLENCE AGAINST NATIVE WOMEN IN SUBSTANCE ABUSE TREATMENT

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Abstract: Many mental health problems among substance abusing populations are directly linked to high rates of abuse and trauma. There is increasing evidence of associations between childhood physical and sexual abuse to adult substance use and HIV- risk behavior. The relationship of abuse, mental health problems, substance abuse, and high-risk sexual behavior has rarely been studied in the female Native American population. Significant relationships were found among childhood abuse, trauma, substance abuse, and high-risk sexual behavior among urban Native women.

Violence is a critical public health issue in the United States, particularly due to its devastating impact on the health and well being of women and children. Recent research on specific types of violence against women have been increasingly persuasive in underlining the association among childhood abuse and neglect, subsequent adult victimization and abuse, trauma experiences, and substance abuse and mental health disorders, especially depression and post-traumatic stress disorder (Kendler et al., 2000; Campbell, 2002). One study revealed that 38% of people who had been sexually abused and 33% who had been physically abused as children experienced PTSD during their lifetime (Widom, 1999). In examining the effects of historic and cumulative lifetime violence on women's health, research has shown that 32 to 68% of women in nonpsychiatric samples report some lifetime experience of physical or sexual assault, with one in five to one in two women reporting multiple abuse experiences (Bohn, 2002). In addition, up to 60% of murders of women in North America are committed by intimate partners (Brock & Stenzel, 1999). Clearly the mental health consequences

of physical or sexual abuse are often severe. Trauma has been associated not only with psychological distress, but also with risky behavior and social role impairment. Traumatized women engaging in substance abuse and unsafe sex are at high risk for contracting HIV/AIDS (Walters & Simoni, 2002; Simoni, Sehgal, & Walters, 2004).

#### **Native Women and Violence**

An important gap in the literature is a lack of information on minority women's experience with violence and its consequences. The above studies are all derived from general population-based samples; when an American Indian/Alaska Native (AI/AN) specific sample is examined, the rates of abuse and associated mental health and substance abuse disorders are significantly higher. Department of Justice statistics reveal that AI/AN women experience two to three times more violent victimizations, including aggravated assault, simple assault, and rape, than women of any other ethnic group in the U.S. (Greenfield & Smith, 1999). The National Center on Child Abuse and Neglect (1999) revealed that 79.8% of American Indian girls had experienced sexual abuse. In a study of the prevalence of child maltreatment and mental disorder outcomes among American Indian women in a primary care setting, Duran et al. (2004) found that 77% of respondents reported some type of childhood abuse or neglect. Neglect was the most commonly reported form of maltreatment, with 63% of respondents having experienced physical or emotional neglect as children. Significantly, nearly 90% of neglected women were also abused; 81% of emotionally abused women were also physically or sexually abused. The lifetime prevalence of mental disorders was highest among women who were both sexually and physically abused as children (Duran et al., 2004). In another study of urban Americans Indians/Alaska Natives in a primary care setting, rates of physical abuse among AI/ANs have been reported to be as high as 46%. Here, victimized individuals had significantly more alcohol use, current depression, history of depression/suicide attempts, and health problems (Buchwald et al., 2000). In one community-based sample, Hobfoll et al. (2005) examined AI women's childhood physical/emotional and sexual abuse and the relationship with later psychological disorders and risky sexual behavior. The study found that child physical/emotional abuse has a greater impact on later psychological distress than does child sexual abuse. In a large community-based study of two tribes, one Southwest and one Northern Plains, for females, the effect of childhood physical abuse on a subsequent PTSD diagnosis was nearly double that of males (Libby et al., 2005). The historical trauma experienced by Native people, often exacerbated by severe sexual abuse, seems to increase the co-occurrence of substance abuse and mental health issues among Native women (Bohn, 2003).

Many women entering substance abuse treatment programs have experienced childhood trauma and alcohol-related violence. Independent of race/ethnicity, women seeking treatment for substance abuse disorders report high rates of violent assault (Noether et al., 2005; Kilpatrick, Resnick, Saunders, & Best, 1998). Between 55 and 99% of women with substance use disorders report being victimized at some point in their life (Najavits, Weiss, & Shaw, 1997). The National Institute on Drug Abuse (NIDA) reports that as many as two-thirds of all people in treatment for drug abuse were physically, sexually, or emotionally abused during childhood (Swan, 1998). The combination of traumatic victimization, mental health issues and substance use leads to a complex clinical dynamic, and although women facing all three of these issues may have more severe troubles and may have more service need, there is limited screening for trauma in most substance abuse programs and a lack of available trauma services (Domino, Morrissey, Chung, Larson, & Russell, 2005).

Though Native women have received little research attention, studies indicate that American Indian/Alaska Native women have an especially high prevalence of all forms of abuse. In an urban San Francisco Bay Area study of Al/AN women receiving substance abuse treatment, 86% of women reported having been physically abused and 69% reported having been sexually abuse during their lifetime (Saylors & Daliparthy, 2004; Saylors, 2003). Very few studies have focused on the relationship between trauma, alcohol and other drugs, and HIV risk in urban American Indian women, though Walters and Simoni (1999) found that substance use mediated the relationship between nonpartner sexual trauma and sexual risk behavior. As well, urban Indian drug users are at greater risk for HIV infection than reservation Indians, because they more frequently trade sex for money or drugs and practice unsafe sex while using drugs (Stevens, Estrada, & Estrada, 2000).

Loss of cultural identity can erode family structure and cultural traditions that discouraged substance use. For American Indians, acculturation stress can become cumulative within communities, and its effects can be experienced over time as "intergenerational grief" (Brave Heart, 2003; Brave Heart & DeBruyn, 1998; Duran, Duran, Brave Heart, & Yellow Horse-Davis, 1998). One way of coping with stress and emotional loss, especially for many younger Native men and women, is

to turn to alcohol, and as a consequence, alcohol-related violence has become quite common. Native women often bear the brunt of violence in drinking situations, which may also place them and their children at extremely high risk for sexual abuse. Many Al/AN women in substance abuse treatment reflect on finding themselves in adult relationships that mirror the abuse they experienced as children or adolescents.

Many American Indian/Alaska Native women use alcohol for escape or relief, however temporary, from anguish linked to past or current experiences of sexual and/or physical violations. For many, cultural identity conflicts have created behavioral, health and lifestyle problems. For urban Natives, the government's Voluntary Relocation Program of the 1950s and 60s uprooted American Indians from their tribal lands and traditions, moving them to West Coast cities where they had to adjust to racism and discrimination in housing and employment, create a new social environment, and rebuild communities. Rapid acculturation changes have contributed to a loss of Native cultural traditions and practices for many urban Als/ANs (Brave Heart & DeBruyn, 1998; Saylors, 2003).

The question thus arises as to whether substance abuse treatment programs are sufficiently responsive to the emotional, social and cultural needs of Native women. Although research has attempted to identify barriers to treatment among women and to learn about what factors predict treatment outcome, little is known about the treatment needs of minority women, especially Al/AN women. Although there has been an increase in programs specifically for women, treatment models are based largely on traditional male programs and may not be responsive to women's needs, especially women from minority groups. Since many addicted women have experienced childhood physical and sexual abuse, exacerbating their powerlessness with models that use aggressive, confrontational or punitive methods can be alienating and often promotes premature dropout. Residential programs that favor a more family-centered, cooperative, and comprehensive approach are more effective for women (Brown, Sanchez, Zweben, & Aly, 1996). Progress has been made in the development of residential treatment programs for female substance abusers and their children, particularly in response to the evidence that the lack of childcare and residence options are major barriers to women entering treatment. Advances have also been achieved in recognizing that women's needs differ from men with respect to patterns of drug use, drug effects, family relationships, victimization histories, and access to treatment. As Prochaska and colleagues' (1992) stages of change model has been clinically adapted to fit women's "levels of immediacy" needs in addressing certain issues over other less prioritized ones, especially in working with women with co-occurring disorders, patterns of recovery suggest that stabilization of substance abuse behaviors may be necessary before gains can be made in reducing mental health and trauma symptoms. (Brown, Melchior, & Panter, 2000; Noether et al., 2005).

#### Method

### **Study Design and Sample**

This study reports information about experiences and effects of alcohol-related violence among American Indian/Alaska Native women entering substance abuse "healing" programs in an urban Native environment. Its chief purpose is to convey information about the nature and extent of such violence, particularly presenting data showing the relationship between childhood victimization, subsequent adult victimization, and substance abuse. Despite increasing recognition of the relationship between victimization experiences and substance abuse among women, there nevertheless remain broad gaps in information about this phenomenon concerning Native women. These findings will have implications pertaining to how treatment programs can best respond to the needs of victimized women.

# **Subjects**

This study examines the findings among American Indian/Alaska Native women in both residential and outpatient substance abuse treatment settings in urban Oakland and San Francisco, California. Longitudinal outcome data were collected at the California sites over a period of 3 years. From September 1999-October 2002, the Native American Health Center (NAHC) in Oakland and San Francisco provided outpatient substance abuse and mental health services to Al/AN women through a CSAT grant (#TI12205): the Women's Circle. NAHC worked in close collaboration with the Friendship House Association of American Indians, which includes a 30-bed residential substance abuse treatment facility in San Francisco and a 5-bed women and children facility in Oakland. The sample includes Native women who received residential and outpatient services under the Women's Circle project. Of the 334 women admitted at intake, 283 or 84.7% were Al/AN. The unduplicated sample for this study is 334.

#### **Data Collection and Assessments**

At intake, staff reviewed our local informed consent procedure with clients, explaining that participation in project evaluation is voluntary and that the data collection procedure is confidential, other than mandated reporting requirements when abuse or threat to harm is mentioned. Once clients understood their human subject protection and signed the informed consent form, a case manager interviewed female participants using the Government Performance Results Act (GPRA) data collection instrument developed by CSAT, along with a supplemental HIV risk assessment and Al/AN supplement which examines potentially relevant sociocultural factors. Through a structured interview, clients were asked to report their usage of alcohol and drugs within the past 30 days; lifetime alcohol and drug use; demographic/background information; history of abuse; health status; legal status; and risk factors for HIV. The client was also asked about cultural and traditional practices that she engages in.

The women who participated in the project were asked to agree to be interviewed at two later dates, 6 and 12 months after intake, using the same data collection instrument. The baseline data was compared to the follow-up data at 6 and 12 months. This allows us to examine trends in outcomes over time, looking for changes in behavior as influenced by substance abuse and mental health treatment, as well as noting important factors in the social and cultural context in urban Native women in the Bay Area.

### Results

Univariate analyses were conducted to provide descriptive information about Native women's experiences with violence, abuse and substance use, with the aim of understanding behavioral relationships between women's experiences of abuse and their subsequent or concurrent substance abuse. Chi-square analyses were used to assess whether the relationships between the experience of previous or current violence or abuse and substance abuse are significant. Correlation between these experiences is substantiated through the data. P values less than 0.05 were considered to be statistically significant, and analyses utilized 95% confidence intervals.

### **Selective Non-Response**

Although little has been written about the effects of response bias and selective non-response around sensitive issues like alcohol and drug use, sexual behavior, and physical, emotional or sexual abuse, our data raise questions about the effect of response bias. Research indicates that selective non-response regarding usage of alcohol and drugs leads to lower, biased estimates of drinking, heavy drinking, and drug use, as well as to lower, biased estimates about the prevalence of problems due to the use of alcohol and drugs. Both of these factors result in biased estimates of the prevalence of alcohol and drug abuse dependence (Caetano, 2001). Along these lines, we attribute some underreporting around the sensitive subjects of illicit drug use, alcohol use, and sexual, emotional and physical abuse, to response bias. Another limitation in the data analysis pertains to the fact that it is often difficult to re-contact clients at follow-up, so there is some variance in the sample size at 6 and 12-month follow-up intervals. Our overall follow-up rate for the project was 73% at 6 months and 54% at 12 months.

# **Prevalence of Violence-Related Experiences**

Female clients were asked about personal violence and related experiences, specifically focusing on whether they had experienced emotional, physical or sexual violence. The data suggests that the majority of the female clients were emotionally abused in their lifetime. Of those interviewed during intake into the Family & Child Guidance Clinic of the Native American Health Center, 89% (n=179) of AI/AN women reported having been emotionally abused during their lifetime. Consistently, this came through in their clinical presentation and was addressed as a treatment issue.

Although our instrument did not capture details regarding intimate partner violence, clients reported a substantial amount of physical violence during their lifetime. Of the sample of Native women served by the program, 84% said they had been physically abused. There is growing evidence of association between family violence (during childhood and adulthood) and women's health. As well, our data suggests that there is a strong association between physical abuse and sexual abuse. A low significance value (0.00 for Pearson chi square, likelihood ratio and linear by linear ratio) indicates that there is strong relationship between the 2 variables of physical and sexual abuse. Of the Native women served by the NAHC program, 67% reported experiencing

sexual abuse in their lifetime. Of those same women, 39% responded affirmatively when asked, "Have you ever been forced to have sexual contact when you didn't want to?" indicating they had experienced coercive sex.

Furthermore, we see high correlations between various types of abuse that women report experiencing. As noted in Table 1, many women who were sexually abused were also physically abused. Specifically, 96.7% of the women in the sample who were sexually abused were also physically abused. Only 78.4% women who reported being physically abused admitted to being sexually abused. Emotional abuse is a constant in all types of reported abuse. For example, of those women who reported being physically abused, 94.7% said they were also emotionally abused, and of those who reported sexual abuse, 95.8% said they were emotionally abused.

Table 1
Correlation Between Various Types of Abuse

	Physical Abuse*		Emotional Abuse*			Sexual Abuse*			
	%	X2	p value	%	X2	p value	%	X2	p value
Physical Abuse	Х	х	Х	94.7	27.217	0.000	78.4	50.945	0.000
<b>Emotional Abuse</b>	88.6	27.217	0.000	х	х	х	72.6	20.392	0.000
Sexual Abuse	96.7	51.579	0.000	95.8	20.941	0.000	х	х	х

<sup>\*94.7%</sup> of the Physically abused women were also Emotionally abused with a X² value of 27.217 and p value of 0.000

Numerous studies have documented a correlation between intimate partner violence and sexual risk behavior for HIV (Raj, Silverman, & Amaro, 2004; Walters, Simoni, & Harris, 2000). In cases where there is a history of intimate partner violence, much of the literature points to a woman's increased vulnerability to HIV risk factors. Such risks arise when a woman's partner controls sex and condom use, and she does not advocate for herself in safe sex practices for fear of the partner's

<sup>78.4%</sup> of the Physically abused women were also Sexually abused with a  $\,X^2$  value of 50.945 and p value of 0.000

<sup>88.6%</sup> of the Emotionally abused women were also Physically abused with a  $X^2$  value of 27.217 and p value of 0.000

<sup>72.6%</sup> of the Emotionally abused women were also Sexually abused with a  $X^2$  value of 20.392 and p value of 0.000

<sup>96.7%</sup> of the Sexually abused women were also Physically abused with a  $X^2$  value of 51.579 and p value of 0.000

<sup>95.8%</sup> of the Sexually abused women were also Emotionally Abused with a  $X^2$  value of 20.941 and p value of 0.000

violent response to safe sex negotiations. In such a case where domestic violence is present, the woman's health may be compromised by her male partner's risk for HIV, such as history of injection drug use, sexually transmitted infections, infidelity in the current relationship, or not getting tested for HIV. What remains unclear is whether a woman's exposure to emotional, physical, or sexual violence makes her more prone to engage in high-risk behavior, whether that be sexually risky behavior or dangerous substance abuse. Although our data collection instrument for the Women's Circle project (1999-2002) did not contain questions about client's trauma experience, PTSD symptoms or intimate partner violence, we have since recognized the need to better understand these dynamics and have added some additional questions into the intake questionnaire, which is part of the Bay Area Red Road (BARR), a local shared database between the Native American Health Center and the Friendship House Association of American Indians that we have built as part of a Strengthening Minority Communities CSAT project (TI13326). At the onset of our current Native Women's project (TI15707) in October 2003, we pilot tested the trauma guestions and in 2004 began collecting these data in order to more comprehensively understand and address trauma within our target population. Although the data are preliminary and the sample is small (n=57), it is part of our efforts to focus on the traumatic experiences of our women clients (Saylors & Daliparthy, 2005).

### **Childhood Violence**

Information on the prevalence of child abuse is provided in Table 2. Of the 63% of clients who reported being physically abused as a child, 22% said that alcohol or drugs were involved in the situation when the violence occurred. In examining the age that abuse first occurred, most often abuse occurred when children were between the ages of 6-10 years old (43%). Of grave concern is the rate of sexual abuse among Native women: This abuse starts early. When we asked female clients whether "as a child someone ever exposed themselves to you or touched you inappropriately," 55.6% said yes. Of those, 37% had this experience between the ages of 1-5 years, and 37% between 6-10 years of age.

Table 2 Child Abuse

	Number	Percent
Yes	36	63.2
No	21	36.8
Total	57	100.0%

# **Adult Violence Experiences**

When clients were asked about whether they have been hit or beaten up as adults, 75% answered affirmatively. Of those who experienced physical violence as adults, 67% said that it was perpetrated either by a current or ex boyfriend, husband, or partner. Of those who had experienced physical violence as adults, 74% of the incidents involved alcohol or drugs. Although the BARR data are preliminary, some important findings emerge from the data. Of the women who reported forced sexual intercourse, 77% said that it had happened more than once. 71% of respondents stated that the person who had forced them to have sex was under the influence of alcohol or drugs. 27% of the women reported that during the incident(s), they were also using alcohol or drugs.

The complex relationships among trauma, substance abuse, and mental health issues raise concerns about the best approach for sustaining recovery. In a qualitative study of female trauma survivors with co-occurring disorders, Harris and colleagues (2005) identified themes around elements that women said helped them in supporting their recovery (connection, self-awareness, a sense of purpose and meaning, and spirituality). The team concluded that women and clinicians must place a high priority on the development of boundary management and other relationship skills, as well as attend to negative feelings and depression to help women develop a strong sense of identity and find meaningful activities to invest in.

#### **Abuse History and Service Use**

In our research, there is a high correlation between a woman's history of any type of abuse during her lifetime and her propensity to seek mental health or substance abuse services, as seen in Table 3. For example, of women who reported being sexually abused, 84% came to the Family & Child Guidance Clinic seeking mental health services, and

56% seeking substance abuse services. Generally, of women who report any type of abuse, 40% have been dually diagnosed with both mental health and substance abuse diagnoses.

Table 3

Co-Morbid Disorders: Relationship Between Lifetime Abuse and Women seeking Mental Health or Substance Abuse Services

If Abused:	Mental Health	Substance Abuse	Dual
Sexually	83.8	56.3	40
Emotionally	85.3	56	40.4
Physically	84	57	40

### Substance abuse

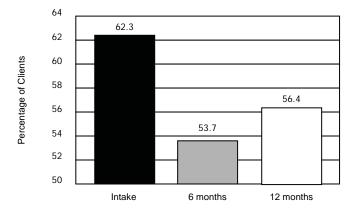
At intake, clients were asked about past 30-day alcohol use. 31.7% of the clients (n=106) said that they had "used alcohol during the past 30 days." The mean number of days of alcohol use was 8.39 days (Cl 6.7-10.1 with SD of 8.8). By 6 month follow-up, the percentage of clients who reported using alcohol during the past 30 days was reduced to 22%, with a mean of 7.26 days of alcohol usage in the past month (Cl 5.1-9.4 and SD of 7.9). Subsequently by 12-month follow-up, the percentage of clients who used alcohol during the past month reduced to 21.4% with a mean usage of 7.56 days (Cl 4.9-10.2 and SD of 8.2). Overall, there was a 10.3% reduction in the number of clients who reported using alcohol during the past month (prior to the interviews at intake, 6 month follow-up and 12 month follow-up), as seen in Figure 1.

35
30
31.7
25
20
20
20
10
5
0
Intake 6 months 12 months

Figure 1
Past 30 Days of Use of Alcohol

Significantly, many of the women served reported drinking alcohol to intoxication, which means drinking five drinks or more in one episode. As noted in Figure 2, of the total clients who reported using alcohol during the past 30 days, 62.3% of them used alcohol to intoxication, with a mean usage of 7.23 days (CI 5.5-9.0 and SD of 7.2). Subsequently, by 6-month follow-up, 53.7% of those who used alcohol in the past 30 days reported that they used alcohol to intoxication. By 12-month follow-up, 56.4% of those who used alcohol in the past 30 days reported using alcohol to intoxication, with a mean usage of 5.4 days (CI 2.5-8.2 and SD of 6.4). Of those clients who drank alcohol in the past 30 days, the percentage of those who drank to intoxication (5+ drinks), was 62% at intake, a significantly high rate of intensive alcohol use.

Figure 2
Past 30 Days Use of Alcohol to Intoxication
(Among Users of Alcohol)



When the women served by NAHC were asked about their drinking history over the course of their lifetime, 88.3% of users of alcohol drank alcohol to intoxication. Women reported a mean of 10 years of alcohol usage (CI 7.9-12.1 and SD of 7.7), with the range of drinking years being between 1 and 35 years.

### Positive effect of culture

Cultural beliefs and Native traditional practices integrated into treatment serve as powerful resiliency factors for clients. Clients were asked questions at intake to get a sense of their cultural orientation, acculturation, and traditional religious practices. The questions help shape the intake case manager's recommendations at case conference, as NAHC employs mostly Native clinicians who integrate clinical psychotherapeutic and traditional practice, as well as inform our understanding of cultural resiliency as a treatment outcome. When clients were asked "How much do you know about your culture?" they responded in the ways noted in Figure 3.

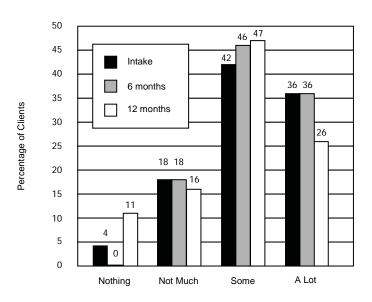


Figure 3
How Much Do You Know About Your Culture?

Significantly, a majority of our clients indicated that they know some or a lot about their culture coming into the program. However, those who reported having a lot of knowledge about their culture reduced their assessment of their knowledge after 12 months. Upon closer examination of the data, this seems to be a consequence of a smaller sample size at 12-month follow-up. In analyzing these responses regarding culture, we separated Native and non-Native clients and found no statistically significant differences in the data.

Clients were also asked "How important it is to you to be Native?" Their responses are noted in Figure 4. Native identity is important for the majority of the clients at NAHC and increases substantially after being involved in the program.

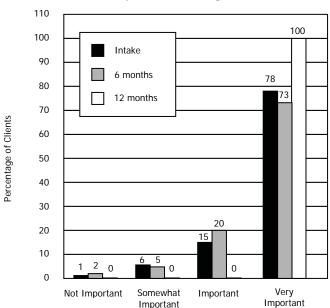


Figure 4
How Important is Being Native to You?

## Conclusion

A significant correlation between violent trauma experiences and mental health issues, specifically PTSD, is underlined by our findings in working with Native women in the urban San Francisco Bay Area. We find consistent reporting that victims of abuse, especially childhood sexual and physical abuse, experience long-lasting psychological trauma. Robin, Chester, Rasmussen, Jaranson, & Goldman (1997) found that both women and men with a history of childhood sexual abuse were significantly more likely to receive diagnoses of three or more psychiatric disorders, compared to subjects with no such history. Further, people who experience PTSD often experience other psychiatric conditions such as depression, other anxiety disorders, and intermittent explosive disorders. Abuse-related PTSD may also increase alcohol and drug use, which is often used as a coping mechanism.

The co-occurrence of traumatic experiences, mental health and substance abuse disorders make for a complex clinical dynamic and

current services delivery systems are often inadequate in treating women with these experiences. "Limited screening for trauma, a lack of available trauma services, extremely fragmented or siloed services that fail to comprehensively address these issues, and a lack of cross-training among services for violence and mental health and substance use disorders are significant barriers to women's recovery" (Domino et al., 2005).

This study posits the close association between experiences of violence, associated trauma in the form of PTSD and other mental health disorders, and drinking, and looks at cultural identity as a mitigating factor for dealing with these trauma experiences. The work done at the Bay Area sites is community based and the data that were collected came from mixed samples of Native women receiving mental health and substance abuse treatment services in both outpatient and residential settings. These data address childhood abuse and the subsequent substance abuse and mental health disorders that appear for these Native women in adulthood. In analyzing the data, we found that client non-response presents a significant limitation to our findings. The effects of selective non-response need to be further investigated and the association between the experience of abuse, substance abuse, and mental health issues needs to be further researched, in particular in Native communities. This study provided a number of observations that we hope will be useful in structuring interventions for women with profound trauma histories. As Villanueva (2003) points out, we may be better able to engender change in clients' substance use and PTSD if we understand American Indian epistemology regarding personal change and combine AI/AN constructs of reconnection and healing with Western clinical treatment paradigms that use psychologically based, empirically validated interventions. The clinical model at the Native American Health Center has aimed at cultural congruence, integrating cultural healing and clinical care, to draw together the strengths of traditional healing approaches (such as Talking Circles or sweat lodge ceremonies), clinical psychotherapy, and evidence-based substance abuse treatment models such as cognitive behavior therapy, motivational enhancement therapy, and family interventions (Saylors & Daliparthy, 2005; Nebelkopf & Penagos, 2005; Bien, 2005). A growing body of literature indicates positive results from approaches that integrate treatment in dealing with the constellation of mental health and substance abuse disorders and a trauma history (Morrissey et al., 2005; Zlotnick, Najavits, & Rohsenow, 2003; Judd, Thomas, Schwartz, Outcalt, & Hough, 2003; Barrowclough, Haddock, & Tarrier, 2001; Ouimette, Moos, & Finney, 2000). When providing substance abuse treatment in Native communities, it is crucial

to create an environment where trust building can occur and which aims to build community and peer support. In order to provide our clients with strength-based, culturally dynamic care, we must understand the nature and repercussions of abuse histories among Native women and how these factors play out in mental health and substance abuse services.

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# GAPS IN DATA FOR AMERICAN INDIANS AND ALASKA NATIVES IN THE NATIONAL HEALTHCARE DISPARITIES REPORT

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The aim of this study was to identify and quantify gaps in health care data for American Indians and Alaska Natives. Findings indicate that only 42% of measures of health care quality and access tracked in the National Healthcare Disparities Report could be used to assess disparities among American Indians and Alaska Natives. Patient safety data was especially limited. Data from American Indians and Alaska Natives need to be improved to allow better targeting of interventions to reduce health care disparities and monitoring the success of these activities.

The National Healthcare Disparities Report (NHDR) is an annual report to Congress on racial, ethnic, and socioeconomic disparities in America (Siegel, Moy, & Burstin, 2004). Goals include identifying important disparities in health care quality and access at the national level and tracking disparities over time. Conditions targeted include cancer, diabetes, end stage renal disease, heart disease, respiratory disease, mental health, and substance abuse. Such information is critical for designing and targeting interventions to improve health care and reduce disparities and monitoring the success of these activities.

Because of the small numbers of American Indians and Alaska Natives included in many federal data collections, at the start of this activity we were concerned that almost no data would be available to examine health care disparities affecting these groups at the national level. Excluding American Indians and Alaska Natives from the report was considered and was rejected as unacceptable. We believed that it would be better to show gaps in information rather than exclude populations from the report.

To our surprise, we found that some national health care information is available on American Indians and Alaska Natives. Consistent with much research (Centers for Disease Control and Prevention, 2003; Denny, Holtzman, & Cobb, 2003; Indian Health Service, 2003a; Liao, Tucker, & Giles, 2003; Roubideaux, 2002; Urban Indian Health Institute, 2004), many disparities in health care affecting these groups were identified and reported in the NHDR (Agency for Healthcare Research and Quality, 2003).

However, data gaps were significant and precluded a comprehensive assessment of disparities faced by American Indians and Alaska Natives. Moreover, gaps in data for American Indians and Alaska Natives were larger than gaps for most other racial and ethnic groups. For example, of measures of quality of health care in the 2004 NHDR that could be tracked over time, data were available for blacks on all measures, for Hispanics on 95% of measures, for Asians on 63% of measures, and for American Indians and Alaska Natives on 55% of measures (Agency for Healthcare Research and Quality, 2004). Of measures of access to health care in the 2004 NHDR that could be tracked, data were available for blacks and Hispanics on all measures, for Asians on 84% of measures, and for American Indians and Alaska Natives on 52% of measures. Hence, compared with other groups, our ability to assess disparities faced by American Indians and Alaska Natives was severely limited.

To begin to fill gaps in data about health care disparities faced by American Indians and Alaska Natives, a better understanding of the reasons for these gaps is needed. Problems with data collection, reliability of estimates, or power to detect disparities may lend themselves to different interventions. In this paper, we use data gathered for the 2004 NHDR to identify and quantify gaps in data for American Indians and Alaska Natives and describe efforts and opportunities to close some of these gaps.

#### Methods

#### **NHDR Measures**

The measures examined in this paper come from the 2004 NHDR. The measures tracked in the NHDR were selected through an extensive process. The Agency for Healthcare Research and Quality (AHRQ), which houses the NHDR, issued a call for measures to Federal agencies. The Institute of Medicine (IOM) issued a complementary call for measures to the private sector. More than 600 measures were submitted for

consideration in response to these calls. An Interagency Work Group, with representatives for across the Department of Health and Human Services, then evaluated these measures based on specific criteria:

- Importance—What is the impact on health associated with the health problem assessed by the measure? Are policymakers and consumers concerned about this area of health care quality? Can the health care system meaningfully address this aspect or problem?
- Scientific soundness—Does the measure actually reflect what it is intended to measure? Does the measure provide stable results across various populations and circumstances? Is there scientific evidence available to support the measure?
- Feasibility—Is the measure in use? Can information needed for the measure be collected in the scale and time frame required? How much will it cost to collect the data needed for the measure? Can the measure be used to compare different population groups?

Effort was also made to maximize consistency with existing consensus-based measure sets and to include both process measures that assess what happens to patients during their care and outcome measures that track what ultimately happens as a result of that care. A proposed measure set was published in the *Federal Register* for public comment and amended accordingly. Each year, the measure set is further refined in response to comments received from Federal partners, private stakeholders, and the public. The full 2004 NHDR quality measure set is listed in Appendix A and the full 2004 NHDR access measure set is listed in Appendix B.

# **Domains of Quality and Access**

The domains of quality examined in the NHDR are based on a conceptual framework developed for AHRQ by the IOM (Institute of Medicine, 2001). In the NHDR, disparities in health care quality are examined across four domains:

- Effectiveness—Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit;
- Safety—Avoiding injuries to patients from the care that is intended to help them;

- Timeliness—Reducing waits and sometimes harmful delays for both those who receive and those who give care; and
- Patient centered—Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

The domains of access examined in the NHDR are based on guidance received from the Interagency Work Group and from the IOM (Institute of Medicine, 2002). Disparities in health care access are examined across another four domains:

- Entry barriers—Measures of the presence or absence of specific resources that enable entry into the health care system, such as having health insurance or a usual source of care;
- Structural barriers—Measures of the presence or absence
  of specific resources that enable receipt of care within the
  health care system, such as having a provider with hours on
  nights or weekends or who can be contacted by telephone
  easily;
- Patient satisfaction—Measures of patients' perceptions of how well their providers interact with them; and
- Health care utilization—Measures of the ultimate outcome of good access to care; i.e., the successful receipt of needed services.

In total, nineteen national databases were used to assess disparities across these domains of health care quality and access in the 2004 NHDR (Table 1). These databases include every major data source capable of providing nationally representative estimates of disparities in health care and that are conducted on a regular basis.

## **Analysis**

In this paper, data gathered for the 2004 NHDR are analyzed to quantify the ability of national data to assess disparities among American Indians and Alaska Natives. Measures rather than data sources are used as the unit of analysis because our goal is to assess the capacity of extant data to provide information about disparities in health care quality and access faced by American Indians and Alaska Natives. Many measures used in the NHDR are restricted to individuals of specific ages or who have specific conditions. Often, data sources that are able to provide reliable estimates for the total American Indian and Alaska Native population

are unable to provide reliable estimates for the subgroups needed to assess quality and access.

# Table 1 Databases Used to Assess Disparities in Quality of and Access to Health Care in the 2004 National Healthcare Disparities Report

#### Surveys collected from samples of civilian, noninstitutionalized populations

- AHRQ, Medical Expenditure Panel Survey (MEPS), 1999-2001
- CDC-NCHS, National Health Interview Survey (NHIS), 1999-2001
- CDC-NCHS/National Immunization Program, National Immunization Survey (NIS), 2000-2002
- SAMHSA, National Survey on Drug Use and Health (NSDUH), 2001-2002

#### Data collected from samples of health care facilities and providers

- CDC-NCHS, National Ambulatory Medical Care Survey (NAMCS), 1999-2001
- CDC- NCHS, National Hospital Ambulatory Medical Care Survey-Outpatient Department (NHAMCS-OPD), 1999-2001
- CDC- NCHS, National Hospital Ambulatory Medical Care Survey-Emergency Department (NHAMCS-ED), 1999-2001
- CDC--NCHS, National Hospital Discharge Survey (NHDS), 1998-2001
- CMS, End Stage Renal Disease Clinical Performance Measures Project (ESRD CPMP), 2001-2002

#### Data extracted from data systems of health care organizations

- AHRQ, Healthcare Cost and Utilization Project State Inpatient Databases disparities analysis file<sup>a</sup> (HCUP), 2001
- CMS, Medicare Patient Safety Monitoring System (MPSMS), 2002
- CMS, Nursing Home Minimum Data Set (MDS), 2002
- CMS, Quality Indicators program (CMS QIO), 2000-2001
- HIV Research Network data (HIVRN), 2001
- NIH, United States Renal Data System (USRDS), 1998-2001

#### Data from surveillance and vital statistics systems

- CDC-National Center for HIV, STD, and TB Prevention, HIV/AIDS Surveillance Report (CDC HIV/AIDS SR), 2001
- CDC-National Center for HIV, STD, and TB Prevention, TB Surveillance System (CDC TBSS), 2000
- CDC-NCHS, National Vital Statistics System (NVSS), 2000-2001
- NIH, Surveillance, Epidemiology, and End Results (SEER) program, 1992-2001

Each measure included in the 2004 NHDR was assessed for one of three different data issues that could preclude use for assessing disparities faced by American Indians and Alaska Natives. Measures were classified as having:

<sup>&</sup>lt;sup>a</sup> This file is designed to provide national estimates of disparities in the AHRQ Quality Indicators using weighted records from a sample of hospitals from the following 22 States: AZ, CA, CO, CT, CT, FL, GA, HI, KS, MD, MA, MI, MO, NJ, NY, PA, RI, SC, TN, TX, VA, VT, and WI.

- Collection issues, if data on American Indians and Alaska Natives were not collected;
- Estimation issues, if data were collected but estimates were unreliable because of small numbers of American Indians and Alaska Natives (< 30) or large relative standard errors (>30%);
- Power issues, if estimates were possible but relative differences compared with whites of 10% were not statistically significant with a two-tailed alpha of 0.05; and
- No problems, if none of these issues were present. Results are presented by domain and by type of data.

# **Findings**

Overall, of the 149 measures of quality of health care tracked in the 2004 NHDR, 42% could be used to assess disparities among American Indians and Alaska Natives (Table 2). Disparities could not be adequately assessed for 21% of measures due to collection issues, 22% due to estimation issues, and 14% due to power issues. Of the 60 measures of access to health care, 42% could be used to assess disparities among American Indians and Alaska Natives. Disparities could not be adequately assessed for 8% of measures due to collection issues, 30% due to estimation issues, and 20% due to power issues.

### **Gaps by Domain**

The ability to assess disparities among American Indians and Alaska Natives differed across domains of quality and access. About half of measures of effectiveness, patient-centeredness, entry barriers, structural barriers, and patient satisfaction could be used to assess disparities among American Indians and Alaska Natives. However, none of the measures of patient safety and only two-thirds of measures of timeliness and health care utilization could be used. Collection issues prevented use of two-thirds of patient safety measures. Estimation issues prevented use of over a quarter of measures of patient safety, timeliness, entry barriers, and health care utilization. Power issues prevented use of over a quarter of measures of timeliness, patient-centeredness, structural barriers, and patient satisfaction.

Table 2
Measures in the 2004 NHDR With Collection, Estimation, or Power Issues by Quality and Access Domains and by Data Type

	Total Measures	Measures with Collection Issues	Measures with Estimation Issues	Measures with Power Issues	Measures with No Problems
	N	N (%)	N (%)	N (%)	N (%)
Quality Domains					
Effectiveness	108	13 (12%)	22 (20%)	15 (14%)	58 (52%)
Patient Safety	28	19 (68%)	8 (29%)	1 ( 4%)	0 ( 0%)
Timeliness	9	0 ( 0%)	3 (33%)	3 (33%)	3 (33%)
Patient-Centeredness	4	0 ( 0%)	0 ( 0%)	2 (50%)	2 (50%)
All Quality Domains	149	32 (21%)	33 (22%)	21 (14%)	63 (42%)
Access Domains					
Entry Barriers	18	0 ( 0%)	5 (28%)	4 (22%)	9 (50%)
Structural Barriers	6	0 ( 0%)	1 (17%)	2 (33%)	3 (50%)
Patient Satisfaction	7	0 ( 0%)	0 ( 0%)	3 (43%)	4 (57%)
Health care Utilization	29	5 (17%)	12 (41%)	3 (10%)	9 (31%)
All Access Domains	60	5 ( 8%)	18 (30%)	12 (20%)	25 (42%)
Data Type					
Person Survey	78	0 ( 0%)	31 (40%)	14 (18%)	33 (42%)
Hospital Discharge	46	37 (80%)	7 (15%)	2 ( 4%)	0 ( 0%)
Long-term Care	22	0 ( 0%)	0 ( 0%)	1 ( 5%)	21 (95%)
<b>Quality Improvement</b>	21	0 ( 0%)	8 (38%)	9 (43%)	4 (19%)
Population Data	20	0 ( 0%)	1 ( 5%)	0 ( 0%)	19 (95%)

Quality Domains: Effectiveness measures care that is based on scientific evidence and generally specific to patients with particular conditions (e.g., cancer). Patient safety measures care that avoids injuries to patients. Timeliness measures care that reduces waits and harmful delays. Patient-centeredness measures care that is respectful of and responsive to individual patient preferences, needs, and values.

Access Domains: Entry barriers measure difficulties getting into the health care system. Structural barriers measures difficulties getting care within the health care system. Patient satisfaction measures patient perceptions of provider communication and relationship. Health care utilization measures actual receipt of health care services.

Data Types: Person surveys include the Medical Expenditures Panel Survey, National Health Interview Survey, National Immunization Survey, Medicare Current Beneficiary Survey, and National Survey on Drug Use and Health. Hospital discharges include the Healthcare Cost and Utilization Project State Inpatient Databases and National Hospital Discharge Survey. Long-term care data include the Nursing Home Minimum Data Set and Home Health Agency Outcome and Assessment Information Set. Quality improvement data include the Medicare Quality Improvement Organization Program and Medicare Patient Safety Monitoring System. Population data include the National Vital Statistics System and various disease registries.

**Notes**: The assessment by data type does not include 22 measures which come from a variety of other data sources that are not listed.

# **Gaps by Data Type**

Data in the 2004 NHDR came from many different sources: population-based surveys, hospital discharge data, long-term care data, quality improvement data, and population data from vital statistics systems and disease registries. The ability to assess disparities among American Indians and Alaska Natives differed across different types of data. About 40% of measures from person surveys could be used to assess disparities among American Indians and Alaska Natives; estimation issues were the major barriers to using these data. No measures from hospital discharge data could be used; collection issues were the major barriers. About 95% of long-term care and population measures could be used to assess disparities among American Indians and Alaska Natives. However, only about 20% of measures from quality improvement data could be used; estimation and power issues were the major barriers.

#### Discussion

In this paper, we identify significant gaps in the ability of extant data to assess health care disparities faced by American Indians and Alaska Natives. Overall, only 42% of measures tracked in the 2004 NHDR had American Indian and Alaska Native estimates that did not have significant issues related to collection, estimation, or power. Large gaps involved all domains of quality and access tracked in the NHDR; a thorough assessment of disparities faced by American Indians and Alaska Natives was not possible for any of these areas.

Data issues varied widely by data type. Population data based on vital statistics and disease registries were largely complete. Long-term care data also could be used to assess disparities among American Indians and Alaska Natives in most instances. Collection of data from Medicare and Medicaid certified nursing homes and home health agencies has been required by the Centers for Medicare & Medicaid Services since the 1990s.

In contrast, no estimates for American Indians and Alaska Natives were possible for measures based on hospital discharge data. This was largely attributable to the fact that many states do not identify American Indians and Alaska Natives in their hospital data. To begin to fill this gap and improve understanding of health care received by American Indians and Alaska Natives, AHRQ and the Indian Health Service (IHS) are collaborating on a project. This project brings together information from the IHS National Patient Information Reporting System (NPIRS) and the

AHRQ Healthcare Cost and Utilization Project (HCUP). Data from NPIRS about discharges from IHS and tribal hospitals (Indian Health Service, 2003b) allow estimates for American Indians and Alaska Natives living in IHS service areas, approximately 56% of the total U.S. American Indian and Alaska Native population (Indian Health Service, 2005). A number of States in HCUP that do collect information about American Indians and Alaska Natives have been identified. Work is currently underway to assess whether data from IHS hospitals and from community hospitals in HCUP with information on American Indians and Alaska Natives can be integrated and weighted to provide national American Indians and Alaska Natives estimates. If feasible, this work would begin to fill the gaps in hospital discharge data for American Indians and Alaska Natives and to allow assessment of disparities in patient safety, which relies heavily upon hospital data.

In addition, person-based surveys and quality improvement data need to be expanded. Options include increasing the numbers of American Indians and Alaska Natives represented in existing national data collections or initiating data collections that focus on American Indians and Alaska Natives, such as the 1987 Survey of American Indians and Alaska Natives (Johnson & Taylor, 1991). Reducing misclassification of American Indians' and Alaska Natives' race in vital statistics (Indian Health Service, 1996) and health care data (Escarce & McGuire, 2003; Korenbrot, Ehlers, & Crouch, 2003; Kozak, 1995) is also important. AHRQ is working with state governments and hospital associations to improve quality and uniformity of race/ethnicity reporting in statewide hospital data systems. IHS is also working with State vital statistics agencies to improve the reporting of American Indian and Alaska Natives on state death certificates (Groves et al., 2004).

The ability to track health care is critical for designing and targeting interventions to improve health care and reduce disparities and monitoring the success of these activities. National health care data too often fail to collect information from American Indians and Alaska Natives that is adequate for generating reliable estimates and assessing disparities experienced by these groups. Without improved data, gaps in the ability to assess disparities in health care among American Indians and Alaska Natives will remain, health care problems may go undetected, and opportunities for reducing disparities may be missed. It is important to reiterate that limited data is not justification for excluding American

Indians and Alaska Natives from national assessments of disparities like the NHDR. Data available for American Indians and Alaska Natives should be presented to identify disparities in need of redress and information gaps in need of remedy.

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# Appendix A 2004 NHDR Quality of Health Care Measures

Measure	Source
Effectiveness: Cancer	
Rate of breast cancers diagnosed at late stage	SEER
Rate of cervical cancers diagnosed at late stage	SEER
Rate of colorectal cancers diagnosed at late stage	SEER
Cancer deaths per 100,000 population per year for all cancers	NVSS
Cancer deaths per 100,000 male population per year for prostate cancer	NVSS
Cancer deaths per 100,000 female population per year for breast cancer	NVSS
Cancer deaths per 100,000 population per year for lung cancer	NVSS
Cancer deaths per 100,000 population per year for colorectal cancer	NVSS
Effectiveness: Diabetes	
Adults with diabetes who had a hemoglobin A1c measurement at least once in past year	MEPS
Adults with diabetes who had a lipid profile in past two years	MEPS
Adults with diabetes who had a retinal eye examination in past year	MEPS
Adults with diabetes who had a foot examination in past year	MEPS
Adults with diabetes who had an influenza immunization in past year	MEPS
Hospital admissions for uncontrolled diabetes per 100,000 population	HCUP
Hospital admissions for short term complications of diabetes per 100,000 population	HCUP
Hospital admissions for long term complications of diabetes per 100,000 population	HCUP
Hospital admissions for lower extremity amputations in patients with diabetes per 1,000 population	NHDS
Effectiveness: End Stage Renal Disease	
Hemodialysis patients with urea reduction ratio 65% or higher	ESRD CPMP
Hemodialysis patients with hemoglobin 11 or higher	ESRD CPMP
Hemodialysis patients with arteriovenous fistula as primary mode of vascular access	ESRD CPMP
Dialysis patients registered on the waiting list for transplantation	USRDS
Patients with treated chronic kidney failure who receive a transplant within 3 years of date of renal failure	USRDS
Effectiveness: Heart Disease	
Current smokers age 18 and over receiving advice to quit smoking	MEPS
AMI patients administered aspirin within 24 hours of admission	CMS QIO
AMI patients with aspirin prescribed at discharge	CMS QIO
AMI patients administered beta-blocker within 24 hours of admission	CMS QIO
AMI patients with beta blocker prescribed at discharge	CMS QIO

Measure	Source
Effectiveness: Heart Disease (continued)	
AMI patients with left ventricular systolic dysfunction prescribed ACE inhibitor at discharge	CMS QIO
AMI patients given smoking cessation counseling while hospitalized	CMS QIO
Heart failure patients with evaluation of left ventricular ejection fraction	CMS QIO
Heart failure patients with left ventricular systolic dysfunction prescribed ACE inhibitor at discharge	CMS QIO
Hospital admissions for congestive heart failure per 100,000 population	NHDS
Deaths per 1,000 adult admissions with acute myocardial infarction	HCUP
Deaths per 1,000 adult admissions with congestive heart failure	HCUP
Deaths per 1,000 adult admissions with coronary artery bypass surgery, age 40 and older	HCUP
Deaths per 1,000 adult admissions with percutaneous transluminal coronary angioplasty, age 40 and older	HCUP
Deaths per 1,000 admissions with abdominal aortic aneurysm repair	HCUP
Deaths per 1,000 pediatric heart surgery admissions, under age 18	HCUP
Effectiveness: HIV and AIDS	
New AIDS cases per 100,000 population 13 and over	CDC HIV/ AIDS SR
HIV-infection deaths per 100,000 population	NVSS
Effectiveness: Maternal and Child Health	
Pregnant women receiving prenatal care in first trimester	NVSS
.ive born infants with low birth weight (<2500 grams)	NVSS
.ive born infants with very low birth weight (<1500 grams)	NVSS
nfant mortality per 1000 live births, all	NVSS
nfant mortality per 1000 live births, birth weight <1500 grams	NVSS
nfant mortality per 1000 live births, birth weight 1500-2499 grams	NVSS
nfant mortality per 1000 live births, birth weight >2499 grams	NVSS
Maternal deaths per 100,000 live births	NVSS
Children age 19-35 months who received all recommended vaccines	NIS
Children age 19-35 months who received 4 doses of diphtheria-pertussis-tetanus vaccine	NIS
Children age 19-35 months who received 3 doses of polio vaccine	NIS
Children age 19-35 months who received 1 dose of measles-mumps-rubella vaccine	NIS
Children age 19-35 months who received 3 doses of Haemophilus influenzae type B vaccine	NIS
Children age 19-35 months who received 3 doses of hepatitis B vaccine	NIS
	NIS

Measure	Source
Effectiveness: Maternal and Child Health (continued)	
Adolescents age 13-15 who received 3 or more doses of hepatitis B vaccine	NHIS
Adolescents age 13-15 who received 2 or more doses of measles-mumps-rubella vaccine	NHIS
Adolescents age 13-15 who received 1 or more doses of tetanus-diphtheria booster	NHIS
Adolescents age 13-15 who received 1 or more doses of varicella vaccine	NHIS
Hospital admissions for pediatric gastroenteritis per 100,000 population	HCUP
Children age 0-17 who had their height and weight measured by a doctor or other health provider	MEPS
Children age 2-17 with advice about physical activity	MEPS
Children age 2-17 with advice about eating healthy	MEPS
Children age 3-6 with a vision check	MEPS
Children agd 0-17 with advice to parent or guardian about smoking in the house	MEPS
Children 0-40 lbs with advice to parent or guardian about using child car safety seats	MEPS
Children 40-80 lbs with advice to parent or guardian about using booster seats	MEPS
Children over 80 lbs with advice to parent or guardian about using lap and shoulder belts	MEPS
Children age 2-17 with advice about using helmets	MEPS
Children age 2-17 with a dental visit	MEPS
Effectiveness: Mental Health	
Suicide deaths per 100,000 population	NVSS
Effectiveness: Respiratory Diseases	
High risk adults age 18-64 who received influenza vaccine in past year	NHIS
Non-institutionalized adults age 65 and over who received influenza vaccine in the past year	NHIS
Hospital admissions for influenza per 100,000 population 65 and over	HCUP
High risk adults age 18-64 who ever received pneumococcal vaccination	NHIS
Non-institutionalized adults age 65 and over who ever received pneumococcal vaccination	NHIS
Pneumonia patients who have blood cultures taken before antibiotics	CMS QIO
Pneumonia patients who receive initial antibiotic dose within 4 hours of arrival	CMS QIO
Pneumonia patients who receive initial antibiotic consistent with current recommendations	CMS QIO
Pneumonia patients who receive influenza screening or vaccination	CMS QIO
Pneumonia patients who receive pneumococcal screening or vaccination	CMS QIO
Deaths per 1,000 adult admissions with pneumonia	HCUP
Antibiotics prescribed at visits with a diagnosis of common cold per 10,000 population	NAMCS NHAMCS
Hospital admissions for asthma per 100,000 population under age 18	NHDS

Measure	Source
Effectiveness: Respiratory Diseases (continued)	
Hospital admissions for asthma per 100,000 population age 18 and over	NHDS
Tuberculosis patients who complete a curative course of treatment within 12 months of initiation of treatment	CDC TBSS
Effectiveness: Nursing Home and Home Health Care	
Long stay nursing home residents who have moderate to severe pain	MDS
Long stay nursing home residents who were physically restrained	MDS
Long stay nursing home residents who spend most of their time in bed or in a chair	MDS
Long stay nursing home residents who had a urinary tract infection	MDS
Long stay nursing home residents who are more depressed or anxious	MDS
Low risk long stay nursing home residents who lose control of their bowels or bladder	MDS
Low risk long stay nursing home residents who had a catheter inserted and left in the bladder	MDS
Short stay nursing home residents with delirium	MDS
Short stay nursing home residents who have moderate to severe pain	MDS
Short stay nursing home residents who have pressure sores	MDS
Home health care patients who get better at getting dressed	OASIS
Home health care patients who get better at taking their medication correctly	OASIS
Home health care patients who get better at bathing	OASIS
Home health care patients who don't get worse at bathing	OASIS
Home health care patients who get better at getting in and out of bed	OASIS
Home health care patients who get better at walking or moving around	OASIS
Home health care patients who get better at going to and from the toilet	OASIS
Home health care patients who have less pain when moving around	OASIS
Home health care patients who have less shortness of breath	OASIS
Home health care patients who have less urinary incontinence	OASIS
Home health care patients who are confused less often	OASIS
Home health care patients who had to be admitted to the hospital	OASIS
Selected infections due to medical care per 1000 discharges	HCUP
Postoperative septicemia per 1000 elective surgical discharges of 4+ days	HCUP
Medicare beneficiaries with central venous catheter-associated infection at insertion site	MPSMS
Medicare beneficiaries with central venous catheter-associated blood stream infection	MPSMS
Medicare beneficiaries with postoperative pneumonia	MPSMS
Medicare beneficiaries with postoperative urinary tract infection	MPSMS
Medicare beneficiaries with ventilator-associated pneumonia	MPSMS
Medicare beneficiaries with hospital-acquired blood stream infection	MPSMS
Postoperative hemorrhage or hematoma with surgical drainage or evacuation per 1000 surgical discharges	HCUP
Postoperative pulmonary embolus or deep vein thrombosis per 1000 surgical discharges	HCUP
Postoperative respiratory failure per 1000 elective surgical discharges	HCUP

Measure	Source
Effectiveness: Nursing Home and Home Health Care (continued)	
Postoperative physiologic/metabolic derangements per 1000 elective surgeries	HCUP
Complications of anesthesia per 1000 surgical discharges	HCUP
Decubitus ulcers per 1000 selected stays of 5 or more days	HCUP
Postoperative hip fractures per 1000 surgical discharges age 18 and over	HCUP
Medicare beneficiaries with postoperative pulmonary embolus or deep vein thrombosis	MPSMS
Medicare beneficiaries with central venous catheter-associated mechanical complication	MPSMS
Accidental laceration or puncture during procedure per 1000 discharges	HCUP
latrogenic pneumothorax per 1000 relevant discharges	HCUP
Reclosure of postoperative disruption of abdominal wall per 1000 abdominopelvic- surgery discharges	HCUP
Foreign body left in during procedure per 1000 discharges	HCUP
Birth trauma injury to neonate per 1000 selected live births	HCUP
Obstetric trauma per 1000 instrument-assisted deliveries	HCUP
Obstetric trauma per 1000 vaginal deliveries without instrument assistance	HCUP
Obstetric trauma per 1000 cesarean deliveries	HCUP
Deaths per 1000 admissions in low-mortality DRGs	HCUP
Deaths per 1,000 discharges with complications potentially resulting from care	HCUP
Persons with provider who does not usually ask about medications other doctors may give	MEPS
<u>Timeliness</u>	
People who have a specific source of ongoing care	NHIS
People in fair or poor health who have a specific source of ongoing care	NHIS
People with a hospital, emergency room, or clinic as source of ongoing care	NHIS
Families that experience difficulties or delays in obtaining health care or do not receive needed care	MEPS
Families that experience difficulties or delays in obtaining health care due to financial or insurance reasons	MEPS
Adults who sometimes or never can get appointment for routine care as soon as wanted	MEPS
Adults who sometimes or never can get care for illness or injury as soon as wanted	MEPS
Pneumonia patients who receive initial antibiotic dose within 4 hours of arrival	CMS QIO
AMI patients administered aspirin within 24 hours of admission	CMS QIO
Patient Centeredness	
Adults whose providers sometimes or never listened carefully to them	MEPS
Adults whose providers sometimes or never explained things in a way they could understand	MEPS
Adults whose providers sometimes or never showed respect for what they had to say	MEPS
Adults whose providers sometimes or never spent enough time with them	MEPS

# Appendix B 2004 NHDR Access to Health Care Measures

Measure	Source
Getting Into the Health Care System	
People under 65 with health insurance	NHIS
People under 65 with any private health insurance	NHIS
People 65 and over with any private health insurance	NHIS
People uninsured all year	MEPS
People with any period of uninsurance during the year	MEPS
People with any period of public insurance during the year	MEPS
People who have a specific source of ongoing care	NHIS
People in fair or poor health who have a specific source of ongoing care	NHIS
People with a hospital, emergency room, or clinic as source of ongoing care	NHIS
People without a usual source of care who indicate a financial or insurance reason for not having a source of care	MEPS
People who have a usual primary care provider	MEPS
Families that experience difficulties or delays in obtaining health care or do not receive needed care	MEPS
Families that experience difficulties or delays in obtaining health care due to financial or insurance reasons	MEPS
Families that did not receive a doctor's care or prescription medications because the family needed the money	MEPS
Families not very satisfied that they can get health care if they need it	MEPS
People who sometimes or never get appointments for routine care as soon as wanted	MEPS
People who sometimes or never get care for illness or injury as soon as wanted	MEPS
Getting Care Within the Health Care System	
People with provider who has office hours nights or weekends	MEPS
People with difficulty getting appointments on short notice	MEPS
People with difficulty contacting provider over the telephone	MEPS
Adults without problems getting referral to a specialist in past year	MEPS
People not very satisfied with professional staff at provider's office	MEPS
People who usually wait over 30 minutes before seeing provider	MEPS
Patient Perceptions of Care	
People with provider who usually asks about medications and treatments other doctors may give	MEPS
Adults whose providers sometimes or never listened carefully to them	MEPS
Adults whose providers sometimes or never explained things in a way they could understand	MEPS
Adults whose providers sometimes or never showed respect for what they had to say	MEPS
People not satisfied with quality of care received from provider	MEPS
Adults whose providers sometimes or never spent enough time with them	MEPS
Adults who rate their health care in the past year <7 on a scale from 0 to 10	MEPS

# Appendix B 2004 NHDR Access to Health Care Measures (continued)

Measure	Source
Health Care Utilization	
People with an office or outpatient visit in the past year	MEPS
People with a prescription medication in the past year	MEPS
People with a dental visit in the past year	MEPS
People with an emergency room visit in the past year	MEPS
People with an inpatient discharge in the past year	MEPS
Outpatient visits per 100 population	NHAMCS- OPD
Emergency department visits per 100 population	NHAMCS- ED
Total hospitalizations per 100 population	NHDS
Medicare beneficiaries 65 and over with Medicare-covered home health care	MCBS
Medicare beneficiaries under 65 with Medicare-covered home health care	MCBS
Medicare beneficiaries 65 and over with nursing home care in the past year	MCBS
Medicare beneficiaries under 65 with nursing home care in the past year	MCBS
Admissions for hypertension per 100,000 population 18 and older	HCUP
Admissions for angina per 100,000 population 18 and older	HCUP
Admissions for chronic obstructive pulmonary disease per 100,000 population 18 and older	HCUP
Admissions for bacterial pneumonia per 100,000 population	HCUP
Admissions for perforated appendix per 1,000 admissions with appendicitis	HCUP
Adults who received mental health treatment or counseling in the past year	NSDUH
Adults who received outpatient mental health treatment or counseling	NSDUH
Adults who received prescription medications for mental health treatment	NSDUH
Adults who received inpatient mental health treatment or counseling	NSDUH
Adults with serious mental illness who received mental health treatment or counseling	NSDUH
People age 12 and older who received illicit drug or alcohol abuse treatment in the past year	NSDUH
People age 12 and older who needed treatment for illicit drug use and who received such treatment in the past year	NSDUH
Hospitalizations for HIV per 10,000 population	NHDS
HIV patients with 4 or more ambulatory visits in the past year	HIVRN
HIV patients with CD4 <50 with 4 or more ambulatory visits in the past year	HIVRN
HIV patients with an inpatient hospitalization in the past year	HIVRN
HIV patients with CD4 <50 with an inpatient hospitalization in the past year	HIVRN

# COMMENTARY DISPARITIES IN DATA FOR AMERICAN INDIANS AND ALASKA NATIVES

Dorothy A. Rhoades, M.D., M.P.H.

Accurate assessment of health disparities across populations requires methods that minimize biases in differences in health characteristics and outcomes. National summaries of disparities among racial and ethnic groups in the United States depend on large, representative, uniform data collection efforts. As emphasized by the Institute of Medicine, standardized data collection is critically important to understand and eliminate racial disparities (Institute of Medicine, 2003).

American Indians and Alaska Natives (Al/ANs) have significant and well-documented disparities in health status compared to the general United States population. Less well documented are disparities in health care for Al/ANs. Although much attention in recent years has focused on disparities in health care in the United States, Al/ANs are often not included in such studies. The National Healthcare Disparities Report is perhaps the most important source of information examining disparities in health care for the U.S. (Agency for Healthcare Research and Quality, 2005). However, Moy and others previously found that the data and measures of quality chosen for use in the National Healthcare Disparities Report, ironically, had limited ability to address racial disparities (Moy, Arispe, Holmes, & Andrews, 2005).

In this issue of American Indian and Alaska Native Mental Health Research: The Journal of the National Center Moy and others focus specifically on the gaps in data for assessing health care disparities for Al/ANs in the National Healthcare Disparities Report (Moy, Smith, Johansson, & Andrews, 2006). The authors quantify deficiencies in national health care data among Al/ANs, revealing that less than half the measures used in the report to assess disparities in health care quality or access can be used for Al/ANs populations. Al/ANs not only experience disparities in health, they also experience disparities in data.

Few reports exist on the disparities of national health data for Al/ANs. One found that older Al/ANs are markedly underrepresented in national datasets. Of 190 large or national health data sets for older age groups, only 13% contained 100 or more Al/ANs aged 65 or older

(Rhoades, 2006). National organizations have also recognized the underrepresentation of Al/ANs. The National Committee on Vital and Health Statistics, for example, concluded that data collection on Al/AN populations is "seriously inadequate" and has called for increased efforts to improve Al/AN information in national datasets (National Committee on Vital and Health Statistics, 2003). A report prepared for the Commonwealth Fund notes that data requirements and methods for collection and reporting vary across federal agencies, and also calls for improvements in racial data (Perot & Youdelman, 2001) as has the Institute of Medicine (Institute of Medicine, 2003).

The lack of measures that can currently be used to assess health care disparity for AI/ANs may be even worse than reported by Moy et al. In particular, racial misclassification should be included as a data collection issue affecting the reliability of estimates of health care disparities even for the adequate sources of data identified. The National Center for Health Statistics, which is responsible for the National Vital Statistics System, evaluated the quality of national vital event data and found that death rates for AI/ANs were underestimated by nearly 21% compared with 11% for Asians and 2% for Hispanics (Rosenberg et al., 1999). The Centers for Medicare and Medicaid (CMS) enrollment database has been compared with data from the U.S. Census and the Medicare Current Beneficiary Survey and found to be less than 60 percent accurate for all racial classifications other than Black or White (Arday, Arday, Monroe, & Zhang, 2000). Such data are obtained through Social Security Administration files, which are incomplete with respect to racial and ethnic data. Completion of forms such as used in the CMS Minimum Data Set, which was also used in the National Healthcare Disparities Report, may not require verification of racial or ethnic group. Similarly, misclassification has plagued Surveillance, Epidemiology, and End Results (SEER) databases in the past, leading to underestimation of the burden of cancer among some Al/ANs (Frost, Taylor, & Fries, 1992).

The Indian Health Service system, which provides health care services for nearly 1.5 million AI/ANs, is developing information systems to improve collection of quality measurements for its patient population (Sequist, Cullen, & Ayanian, 2005). Plans include creation of a Data Warehouse capable of integrating both administrative and clinical data within one repository. Use of measures comparable if not identical to those tracked by the National Healthcare Disparities Report would add greatly to our understanding of health care disparities. However, these efforts will still leave gaps in information for the entire AI/AN population and continued improvements in national data collection are required.

As Mov et al. (2006) point out, national data frequently fail to collect adequate information for generating reliable estimates for Al/ANs, which may lead to undetected health care problems and missed opportunities to reduce disparities. Indeed, an example of how such disparities in data collection led to underrecognition of a serious public health problem is the impact of cardiovascular disease among Al/ANs (Rhoades, 2005). National vital event data, such as used in the National Healthcare Disparities Report, consistently suggest that CVD mortality rates among Al/ANs compare favorably to the general population. However, these studies do not account for the effect of racial misclassification, which disproportionately affects Al/ANs. Adjustment for racial misclassification by the Indian Health Service (Indian Health Service, 1996, 2004) as well as the population-based epidemiologic Strong Heart Study (Howard, et al., 1999; Lee, et al., 1998) demonstrated that Al/ANs actually have higher, not lower, mortality from CVD and that this disparity is increasing. Dependence solely on vital event data for mortality outcomes would have resulted in a continued and serious underestimation of the extent of the problem of CVD, the leading cause of death for Al/ANs. One wonders what major problems in health care for AI/ANs have already been overlooked due to the poor quality of national comparative data.

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