Urban American Indian/Alaska Native Maternal, Infant and Child Health Capacity Needs Assessment

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Executive Summary

Introduction

In an effort to better understand the maternal, infant and child health (MICH) services available to urban American Indians and Alaska Natives; we conducted a MICH Capacity Needs Assessment. We surveyed the 34 urban Indian health organizations (UIHO) nationwide. The survey included questions about the populations served and the services provided to women, infant, child and youth groups. Descriptive analyses were used to summarize information about site accessibility, quality and affordability of services in aggregate. Potential barriers to care for women, infant, child and youth clients were also assessed. The findings of the assessment may be used to identify specific areas where greater attention is needed to enhance services for women, infants, children and youth.

Key Findings

Demographics

- Twenty-four sites participated in the survey (Response rate 71%).
- A total of 99,317 clients were seen in the past year for 23 sites with available data with 53% (N=52,785) reported to be American Indian/Alaska Native (AI/AN).

Services

- Sexual health services such as contraception, pregnancy/sexually transmitted infection/HIV testing and counseling are provided onsite or by referral for the majority of sites, although abortion is not offered by 35% of sites.
- Most sites provide or refer for services for pregnancy and infant health services such as immunizations, well-child visits and parenting support, but a large portion of sites do not offer maternity case management, childbirth classes, or home visits/public health nurse visits.
- A broad range of mental health/social services are provided by participating sites, but 27% of participating sites do not offer SIDS counseling.
- Traditional health services are offered onsite or by referral for 65% of sites.

Accessibility

- Forty-eight percent of sites (N=11) had shortages of providers or services and 70% (N=16) had shortages of resources/funding for providing MICH services.
- Forty-five percent of sites (N=10) reported out-of-pocket costs posed a barrier to care for children, women or pregnant women at their site.
- Eighty-seven percent of sites (N=20) provided transportation assistance to their site. Types of transportation provided were: bus 46%, taxi 37%, shuttle 50% and other types 21%.
- One site offers informal childcare.
- Out of 19 sites with available data and that provide services for a fee, the average percent of clients covered by Medicaid is 34% and the average percent who were uninsured was 39%.

Quality

- Eighty-three percent of sites (N=19) report care was coordinated for clients for services from different agencies in the community.
- Seventy-eight percent of sites (N=18) report care within their site was coordinated for clients.
- Forty-six percent of sites (N=11) have culturally specific MICH programs for AI/AN (i.e. traditional diet, cradleboard classes, AI/AN group leaders, etc).
- Sixty-four percent (N=14) of sites provide care to children with special healthcare needs (CSHCN).
- Of those sites who provide care to CSHCN, 75% (N=12) report care for CSHCN was family-centered.
- Survey participants were asked to describe any quality assurance (QA) or quality improvement (QI) activities in place for MICH services. Quarterly QA or QI committee meetings, QA surveys, staff and advisory board meetings, chart reviews and monitoring and reporting were mechanisms used to assess quality of services.
- Tracking immunization and well-child visit rates, Government Performance and Results Act (GPRA) indicators and program monitoring of high risk indicators were outcomes used to measure the effectiveness of MICH programs.

Need

- The need for OBGYN and dental care providers were mentioned specifically by site representatives and were reported as unmet needs by both clients and providers.

Conclusions

The findings of this capacity needs assessment highlight current areas of strength as well as areas of need in providing maternal, infant and child health care to urban AI/AN. Findings show a need for additional pregnancy and infant health services at many sites. Between 22% and 35% of sites do not offer or refer clients for maternity case management, childbirth classes, home visits/public health nurse visits and SIDS counseling. Greater than 17% of sites do not offer or refer clients for newborn screening, lactation support, and prenatal and pediatric dental services. The need for additional pregnancy and infant health services was illustrated by the large number of sites reporting provider/service shortages and shortages of resources/funding for MICH services. However, despite these shortcomings, the high quality of care provided by UIHO is demonstrated by the large number of sites reporting care coordination both within the site and with other agencies.

The information in this report may be used by UIHO to allocate resources, design effective programs and guide evaluation of services. Information from the survey, including gaps in services, may also be used along with data on the health status of urban AI/AN to further justify the need for the urban Indian health program. Available data on maternal and child health show a number of areas that put urban AI/AN at risk for adverse birth outcomes and significantly increased rates of infant mortality compared to the general population. Increased resources to support maternal and child health services offered by urban Indian health organizations may hold promise for reducing the observed disparities.

Introduction

The Urban Indian Health Institute (UIHI), a division of the Seattle Indian Health Board (SIHB), in Seattle, Washington was founded in 2000. The mission of the UIHI is to provide centralized nationwide management of health surveillance, research, and policy considerations regarding the health status deficiencies affecting urban American Indians and Alaska Natives (AI/AN).

The UIHI received Indian Health Service (IHS) funding in 2004 to conduct maternal and child health (MCH) epidemiology activities focused on the urban AI/AN population nationwide. As a result of this funding, a capacity needs assessment was proposed in order to help identify areas of greatest need, as well as potential intervention, in this population. A list of MCH priorities generated from the capacity needs assessment was also viewed as a future guide for program planning and allocation of resources.

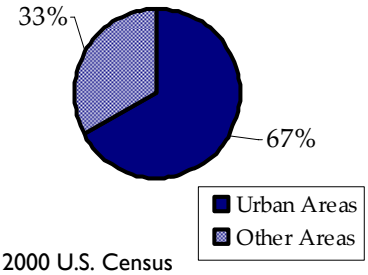
The UIHI conducted a Maternal, Infant and Child Health Capacity Needs Assessment to ascertain the maternal, infant and child health (MICH) services as well as the accessibility, quality, and affordability of those services provided by the 34 urban Indian health organizations (UIHO) funded through Title V of the Health Care Improvement Act.. The purpose of the assessment was to assist in identifying specific assets, limitations or gaps in the urban Indian health program as a whole. The findings of the assessment may be used to increase awareness and understanding of program needs, improve stability of funding for the urban Indian health program and help advocate for the populations served.

Background

Urban American Indian/Alaska Native Population

According to the 2000 U.S. Census, more than 4.1 million persons self-identified as either American Indian or Alaska Native (AI/AN) alone or AI/AN and some other race or ethnicity, and approximately 2.5 million identified as AI/AN race alone.[1] 67% (2.8 million) reside in urban areas (Fig. 1)––a number nearly double what it was 30 years before.[2]

Figure 1 Percentage of U.S. AI/AN Population Living in Urban Areas



Source: 2000 U.S. Census

Urban Indian Health Organizations

The UIHI serves and provides technical assistance to 34 urban Indian health organizations (UIHO) in 94 select urban counties in 19 states across the country (See Appendix C for a list of UIHO states and service area counties).[3] All of the UIHO are private not-for-profit organizations that receive various amounts of funding from Title V of the Indian Health Care Improvement Act. One third of the UIHO are federally qualified health centers, which allows them to receive additional funding from Medicaid; however all provide sliding scale payment systems for their clients. The UIHO vary in their sizes and services provided; these may range from community outreach to comprehensive medical care. Many UIHO clients are unable to access IHS or tribally-run health services because of geographic inaccessibility or Tribal eligibility restrictions. UIHO serve a vital role in assuring access to primary medical care for

the low-income urban AI/AN population, yet UIHO receive approximately 1% of the overall IHS budget.

Maternal and Child Health among Urban American Indians and Alaska Natives

There is a paucity of information about the health of urban AI/AN. This may be due to the challenges of analyzing small-population size per urban area respective to the total population as well as misclassification errors of race/ethnicity on vital statistics records. Despite these limitations, several recent studies observed disparities between urban AI/AN and the general population in the area of MCH.

In a recent study of AI/AN in the 34 UIHO service areas (referred to here as "urban"), Castor et al identified significant disparities between both urban and non-urban AI/AN populations and the general population in a number of poor birth outcome risk factors.[4] Disparities between AI/AN and the general population in urban areas specifically included the rate of births to: teenage mothers (8.2% and 4.6%, respectively), unmarried women (60.3% and 34.8%, respectively), women who received late to no prenatal care (9.8% and 5.0%, respectively), and women who consumed alcohol (5.2% and 1.5%, respectively) or smoked while pregnant (17.2% and 10.7%, respectively). Among a host of other socio-economic factors, the study found higher rates of disability, more single parent households, higher rates of poverty, lower levels of formal education, and higher unemployment among urban AI/AN.

While birth rates in general were lower in the urban AI/AN population (12.8 and 16.5 per 1,000 population, respectively), premature birth rates for both urban and non-urban AI/AN were higher than those of all other races and ethnicities combined (12.3% of live births among AI/AN in urban areas and 10.9% among the general population in the same areas).[5]

With regard to infant mortality, AI/AN rates in UIHO service areas did not decline despite their significant decrease for the general population. Factors associated with AI/AN infant deaths were unwed motherhood, maternal smoking and alcohol consumption, teenage motherhood, and late or no prenatal care. Rates of infant mortality due to maternal alcohol consumption in urban areas were 9.1% among AI/AN compared to 2.2% in the general population. Additionally, sudden infant death syndrome (SIDS) rates for urban AI/AN were at least double those observed in the general population. Again, while the rates of SIDS were found to decrease in the general population, this did not hold true for the urban AI/AN population.[6]

A 1990 study of infant mortality among AI/AN populations found that between 1966 and 1985, infant mortality rates for the AI/AN population dropped from 36.8 deaths per 1,000 live births to 9.7 per 1,000 live births. Much of this decline was due to the reduction of postneonatal mortality rates, defined as "deaths occurring between 28 days to 11 months after birth", attributable to improvements in immunization rates, among other things. Some factors that contributed to the infant mortality included substance abuse and alcohol use during pregnancy, the latter of which impacts the incidence of fetal alcohol syndrome (FAS). Additionally it was found that in 1990, 40% of postneonatal deaths and 24% of infant mortality rates among AI/AN were attributed to SIDS.[7]

A retrospective cohort study conducted by Grossman et al, analyzed linked birth-death data from 1989 to 1991 and found that nearly 15% of urban AI/AN women did not receive adequate health care during pregnancy.[8] In this study, it was found that almost 6% of all AI/AN births were LBW. The infant mortality rate among AI/AN for this time period was 11 deaths per 1,000 births, which was almost evenly distributed between neonatal and postneonatal deaths. The majority of babies were born to AI/AN women ages 18–34 years of age with about 7% born to mothers under the age of 18 years.

Grossman and colleagues concluded that although UIHO existed in most cities with large birth counts, many had inadequate resources to meet existing needs to improve perinatal outcomes and infant health. The metropolitan areas with the highest number of AI/AN births with an UIHO included: 1) Los Angeles/Orange County, CA, 2) Phoenix/Mesa, AZ, 3) Tulsa, OK, 4) Seattle/Tacoma/Bremerton, WA and 5) Albuquerque, NM. Grossman and colleagues found that direct medical care or outreach services for urban AI/AN populations are available in these areas, though in some cases the amount of need for care and the services available were not necessarily compatible. In the case of the Los Angeles-Orange metropolitan area, for example, direct prenatal care services were not offered through an UIHO despite having the highest number of AI/AN births among metropolitan areas.[9]

The areas with the highest rates of inadequate prenatal care, highest proportion of AI/AN LBW babies and highest neonatal and postneonatal death rates during 1989-1991 are shown in Table A.[10]

Table A. List of Top 5 Cities by Rank on AI/AN MCH Indicators, 1989-1991 (Grossman)

Rank	Inadequate Prenatal Care	Low Birth Weight	Neonatal Death Rate	Postneonatal Death Rate
1	Minneapolis/ St. Paul, MN	New York City, NY	Buffalo/ Niagara Falls, NY	Yakima, WA
2	Yakima, WA	Boston area, MA	Providence, RI	Minneapolis/ St. Paul, MN
3	Billings, MT	Philadelphia/Wilmington/ Atlantic City area, NJ	Fall River/Warwick, MA	Redding, CA
4	Yuma, AZ	Great Falls, MT	Yakima, WA	Bakersfield, CA
5	Bellingham, WA	Washington DC/ Baltimore, MD	Bellingham, WA	Reno, NV

AI/AN=American Indian/Alaska Native; MCH=maternal and child health

Looking at tribal populations, IHS published a report in 1992 entitled "Indian Babies who Die: A Comparison with those who Survive the First Year of Life," which examined factors that made the difference between babies in the AI/AN community that survived past one year of age and those that didn't. Factors that increased infants' chances of survival include: birthweight greater than 2500 grams, length of gestation greater than 37 weeks, first order birth, prenatal care in the first trimester and higher Apgar score*. Correlations were also drawn between specific

causes of death and particular factors, including individually both SIDS and congenital anomalies, with age at death, LBW, age of mother, and prenatal care. [11]

** A measure used to evaluate an infant's physical condition at one and five minutes after birth and is used to predict an infant's chances of surviving the first year of life. Infants are tested on five factors: heart rate, respiratory effort, muscle tone, reflex irritability and color.*[12]

Capacity Needs Assessment

To assist in identifying priorities and moving to address areas of greatest need, the Title V MCH Block Grant mandated a Needs Assessment. This was used as the template for our MICH Capacity Needs Assessment. According to the U.S. Department of Health and Human Services' Health Resources and Services Administration (HRSA), "a strong substantive analysis of needs and system capacity, and a clear linkage of priorities to those needs" are essential. This analysis helps to define the focus of intervention activities, which may facilitate support from various stakeholders and potentially make intervention efforts more effective.[13]

Health Resources and Services Administration states, "A thorough needs assessment has two major components: an assessment of population needs, and an analysis of the capacity of systems to meet these needs."[14] Assessing capacity includes identifying accessibility of MCH services, determining the quality of these services, and their affordability. Four steps are outlined for the identification of MCH capacity, including the assessment of: "1) direct and enabling services; 2) population-based services; 3) infrastructure-building capacity within the agency to build and support a quality MCH system; and 4) individual and organizational assets available to support and improve the MCH system."[15]

Components of steps 1 and 2 were the focus of our MICH Capacity Needs Assessment of UIHO—health care facilities for urban AI/AN. Step 1, assessing services capacity, involves choosing a focus for health services, conducting an inventory of existing resources (affordability, accessibility, quality, effectiveness, etc) and then compiling data to support the capacity of these identified resources to serve as indicators, followed by the organization of the assessment itself.[16] Step 1 also includes identifying issues that might impact service capabilities, such as budgetary concerns, or new regional government policies. Step 2 consists of assessing the capacity of population-based services, such as determining what proportion of the population that could potentially access the service is actually doing so, and whether services are language-appropriate or culturally competent.

Methods

Survey Instrument

The MICH Capacity Needs Assessment survey identifies the current services offered, the demographics of the women, infant and youth clients served and the accessibility, quality and affordability of those services. Potential barriers to care for women, infant and youth clients were also assessed. The survey design was intended to complement state and national activities by including Healthy People 2010 Goals and applicable Title V MCH Block Grant national performance and outcome measures. The UIHI chose 18 MCH National Performance Measures from HRSA's Title V Block Grant Program to base survey questions on (see Appendix A). The use of national performance measures will allow comparisons with results from other healthcare organizations/systems.

Survey Implementation

An email which described the survey and encouraged participation was sent to the Executive Directors of the 34 UIHO. The Executive Directors were asked to appoint appropriate staff members from their site to complete the survey. Survey participants were asked to seek out information from within their organization in order to respond to survey questions and were encouraged to provide the best estimate available. Also, participants were able to respond to questions by checking "Don't know" or "Refused" and are presented as such. UIHO were given the option of completing the survey on the computer using a secure website or completing a paper version of the survey. Three reminders were sent to all 34 UIHO and at least 10 additional attempts were made to contact individuals to request participation.

Data Analysis

Urban Indian Health Institute staff members entered data from the paper surveys into the web-based data entry system. Data was entered by two separate UIHI staff members and any discrepancies were resolved by going back to the paper form or by follow-up with participants to ensure accurate data entry. Analyses were performed using STATA software version 8.2.[17]

Descriptive analyses were conducted to show the responses in aggregate. Survey participant comments are quoted verbatim and are listed in italics in bullet format in each section. Changes made for the purpose of clarification from comments on written surveys, from elucidation received verbally or via email by participants are shown in brackets. Comments that included information which would identify a participant's site are not presented to protect the confidentiality of the site and these modifications are shown in brackets. Response frequencies and percent estimates are reported. Sites with missing data are removed from the denominator when calculating percent estimates for each question and are noted in tables as "Data not available".

Results

A total of 24 sites participated in the survey (Response rate= 71%).

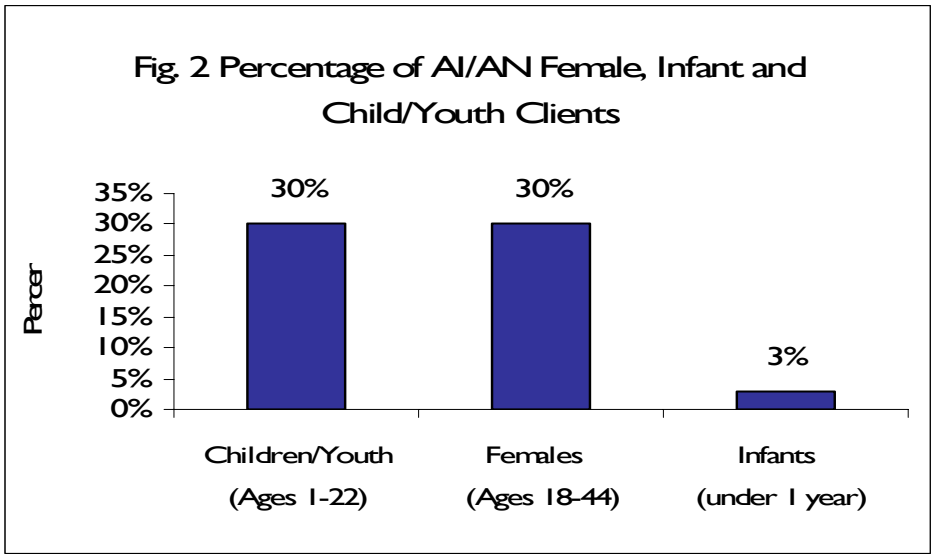
Demographics

A total of 99,317 clients were seen in the past year for 23 sites with available data on client numbers; 53% (N=52,785) were American Indian/Alaska Native (AI/AN).

Twenty-three sites provided data on the numbers of female, infant and children/youth clients. Of the AI/AN clients seen at 21 of these sites, 3% were infants under 1 year old, 29% were children and youth between the ages of 1-22 and 28% were females between the ages of 18-44 (Infants: N=1,423; Range 0 to 11%, Children/Youth: N=13,090; Range 19 to 70%, Females: N=12,708; Range 19 to 91%).

Two sites reported slightly different age ranges, which correspond to the Indian Health Service Urban Indian Health Program Common Reporting Requirements (UCRR). Of the 7,810 AI/AN clients seen at these two sites, 4% (N=304) were infants under 1 year old, 52% (N=4055) were children and youth ages 1-24 and 57% (N=4,474) were females ages 15-44.

Figure 2 shows the total percentages of children/youth, females and infants at the 21 sites with data on these groups, not including the sites who offered data on different age groups.



Percent estimates based on 21 sites with available data on these groups

Services

Table 1 lists the number and percent of sites offering services and the level in which those services are offered. Twenty-three sites provided this data, except where otherwise noted.

Table 1: Number and Percent of Sites Providing Services by Level of Provision

Type of Service	Onsite or Both* N (%)	Referral N (%)	Do Not Offer/Refer N (%)
Sexual Health			
Contraception	19 (82.6)	4 (17.4)	0 (0.0)
Pregnancy Test	19 (82.6)	4 (17.4)	0 (0.0)
Abortion Service	0 (0.0)	15 (65.2)	8 (34.8)
STD Testing (**N=21)	18 (85.7)	3 (14.3)	0 (0.0)
HIV Testing and Counseling	19 (82.6)	4 (17.4)	0 (0.0)
Pregnancy and Infant Health	10 (43.5)	11 (47.8)	2 (8.7)
Prenatal Care	9 (39.1)	9 (39.1)	5 (21.7)
Maternity Case Management	4 (17.4)	11 (47.8)	8 (34.8)
Childbirth Classes	12 (52.2)	7 (30.4)	4 (17.4)
Newborn Screening	10 (43.5)	10 (43.5)	3 (13.0)
Early Hearing Loss Screening	14 (60.9)	6 (26.1)	3 (13.0)
Lead Screening	12 (52.2)	7 (30.4)	4 (17.4)
Lactation Support	20 (87.0)	3 (13.0)	0 (0.0)
Immunizations	18 (78.3)	4 (17.4)	1 (4.4)
Well Child Visits			
Home Visits/Public Health Nurse Visits	15 (65.2)	3 (13.0)	5 (21.7)
Parenting Support	19 (82.6)	2 (8.7)	2 (8.7)
Prenatal Dental	9 (39.1)	10 (43.5)	4 (17.4)
Pediatric Dental	9 (39.1)	10 (43.5)	4 (17.4)
Women's Health			
Preconception or Interconception Care	16 (69.6)	3 (13.0)	4 (17.4)
Well Women's Exam	18 (78.3)	5 (21.7)	0 (0.0)
Nutrition	20 (87.0)	2 (8.7)	1 (4.4)
Dental	11 (47.8)	11 (47.8)	1 (4.4)
Mental Health/Social Services			
SIDS Counseling (**N=22)	11 (50.0)	5 (22.7)	6 (27.3)
Domestic Violence Counseling (N=24)	18 (75.0)	5 (20.8)	1 (4.2)
Mental Health Counseling (N=24)	21 (87.5)	3 (12.5)	0 (0.0)
Smoking Cessation (N=24)	19 (79.2)	4 (16.7)	1 (4.2)
Substance Use Counseling	5 (26.3)	3 (15.8)	0 (0.0)
WIC/Food Assistance/Food Bank	3 (15.8)	10 (52.6)	1 (5.3)
General			
Laboratory	17 (73.9)	5 (21.7)	1 (4.4)
X-Ray (**N=22)	1 (4.6)	19 (86.4)	2 (9.1)
Pharmacy	10 (43.5)	11 (47.8)	2 (8.7)
Traditional Health	15 (65.2)	4 (17.4)	4 (17.4)

*Both=Onsite and referral, **Missing data; percent estimates based on responding sites

Accessibility

Waiting Time for Appointments

The average length of time that clients wait to get an appointment of any type was reported as 6.9 days (Range 0 to 45 days). The average waiting time reported for clients to be seen while in the clinic was 17.9 minutes (Range 0 to 52.5 minutes).

Shortages: Providers or Services

Forty-eight percent of responding sites (N=11) reported shortages of providers or services. Comments regarding provider shortages included:

- *Limited provider services, no Medical Doctor, no social services or patient advocate personnel, no mental health except for chemical dependency*
- *[Shortage of] culturally competent providers for uninsured*
- *Looking for Nurse Practitioner, stable Medical Doctor and part time Obstetrician*
- *Difficult to recruit to [site geographic] areas*
- *Dental*
- *Having issues getting [patients] into dental for pregnancy*
- *Almost all providers got pregnant! So we needed to get temps*
- *No OBGYN services on site, county hospitals are thought to deny Medicaid clients*
- *[Shortage of] specialized health services*
- *Prenatal services limited*
- *Not enough exam rooms*
- *[Shortages of] part-time doctor, part-time nurse, and part-time RD tech*

One site elaborated on shortages experienced stating that there is more need than availability of dental provider time. They provided the examples of being triple booked for appointments to get patients in during pregnancy and having to refer patients with coupons to other locations for urgent needs.

Some sites commented on the difficulty of recruiting providers. Facility site location and the lack of eligibility for Public Health Service and loan repayment incentives were cited as factors that reduced the success of recruitment. The need for stable and part-time providers was also mentioned.

Shortages: Resources and Funding

Specific issues related to resource and funding shortages were cited as:

- *Limited services on site…*
- *Shortage of accessible culturally-competent services for uninsured*
- *We need OB services and an MCH nurse - no money for this*
- *Decreased or threatened federal funding*
- *We would like to offer more services on-site*
- *Limited funding*
- *Minimal resources available; lack of funding; many clients travel over three hours for specialty services*
- *[Lack of childcare. It can take 2-6 weeks to receive medical coupons.]*

- *Funding for several services [is available] for teens only*
- *[Shortages of resources and funding for] dental*
- *Can't hire any new staff for onsite prenatal care, loss of pediatric patients as a result*
- *Can not offer prenatal, malpractice insurance is too high*
- *We need dental, vision, hearing on-site services and midwife services*

One site explained that some of the current resource/funding shortages did not always exist and offered that subsidies used to be provided for medications from the pharmacy, such as prenatal vitamins, but these are no longer available.

Out-of-Pocket Costs

Forty-five percent of responding sites (N=10) reported that out-of-pocket costs pose a barrier to care for children, women or pregnant women at their site (two sites responded "Don't know" and one outreach and referral site responded with "Refused" commenting that the question is not applicable to them). Specific comments included:

- *Costs of care are zero for patients, services are limited. Could do more if more money, like home visits, case mgmt, childbirth classes, parenting support, domestic violence abuse counseling, smoking cessation - do these, but very limited, sometimes teens only*
- *No charge for services at our site, but our services are quite limited*
- *Sometimes, we can only provide primary care services and sometimes women or children need services we can't provide and if they are uninsured it's hard to set them up with specialist in a timely fashion*
- *Especially for co-pays on meds; if not on Medicaid*
- *This population is generally single parent and low income*
- *Uninsured patients may be reluctant to apply for Medicaid*
- *Clients do not come in for services because they can't afford them*
- *Lack of ability to pay co-pays*
- *Money for co-pays for referrals*
- *Money for prescriptions*

Reporting Mechanism for Unmet Need: Clients

Eighty-seven percent of responding sites (N=20) reported having a mechanism for clients to report unmet need. Examples of mechanisms for clients to report unmet need included:

- *We try to do an annual community survey*
- *Client comment box and surveys we pass out quarterly to the main clinic clients, but also to our diabetes and women wellness program participants*
- *We provide a client satisfaction survey for clients to fill out and share their concerns, needs and feedback regarding the services they received*
- *Annual survey, cQI*
- *[Site specific] complaint forms*

Sites with a mechanism for clients to report unmet need described such areas of need as:

- *CHIPS, Medicaid, Medicare and Tribal Enrollment*
- *Dental, vision, specialist care*
- *Childcare*

- *Length of time to obtain dental clinic appointment*
- *No dental providers who accept Medicaid in the city*
- *No OBGYN or Pediatrician on site, Dietitian comes once a month*
- *Comprehensive dental*
- *Difficulty scheduling, so often call other staff to assist*
- *Need transportation to pharmacy and specialty care; need more home care for elderly; need childcare*
- *Varies based on client circumstances*
- *Lack of insurance, lack of transportation*
- *[Need for] food*
- *Often transportation issues*

Reporting Mechanism for Unmet Need: Providers

Fifty-two percent (N=12) of sites reported having a mechanism for providers to report clients' unmet need at their site (one site responded "Don't know"). Examples of mechanisms for providers to report clients' unmet need were as follows:

- *Referred to Health Center Director*
- *At meetings such as our clinical services or pharmacy and therapeutics meetings. We also have a "non-covered" service request form providers fill out for a patient with a need*
- *Just all-staff, med staff meetings*
- *Informal only*

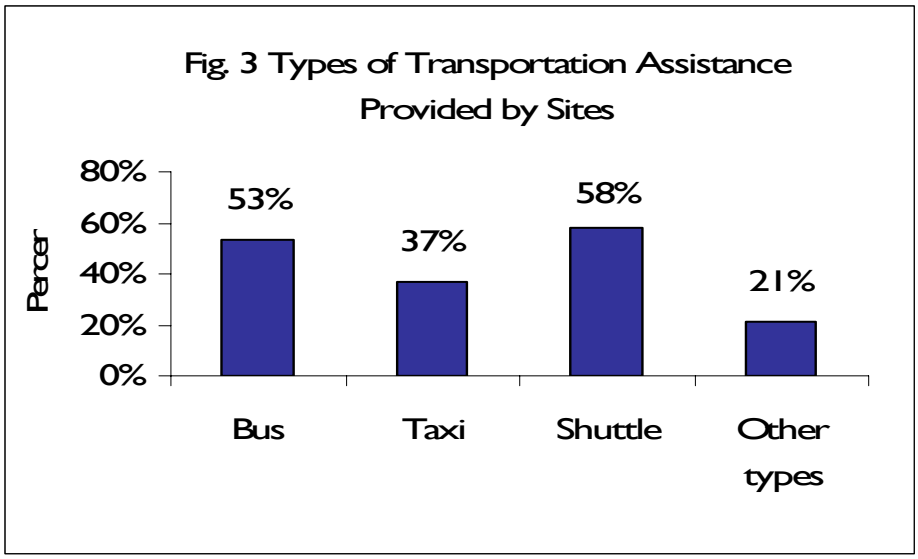
Sites with a mechanism for providers to report unmet need described such areas of need as:

- *Dental, vision, specialist care*
- *Sometimes medication or certain tests are unavailable; these patients are referred to[Tribal] service unit*
- *Accessibility of diagnostic testing*
- *Financial assistance for specialty care*
- *Same as reported by clients and clients inability to negotiate support systems to apply for eligible services such as Medicare, WIC, SSI, etc*

Transportation

Eighty-seven percent of responding sites (N=20) provide transportation assistance to their site. Figure 3 shows the types of transportation provided. Other types included:

- *Two-way private bus transportation for prenatal care and elderly/disabled, one-way home for other care, taxi after-hours for the evening clinic*
- *Agency transportation to local IHS clinic and/or local medical appointments,*
- *[State] transportation broker*
- *CHR van*
- *Coordination of rides with medical transportation, and referral to volunteer rides through non-profit agencies*
- *Transportation and gas cards for very low income diabetes patients*
- *Taxi to [other clinic] site*



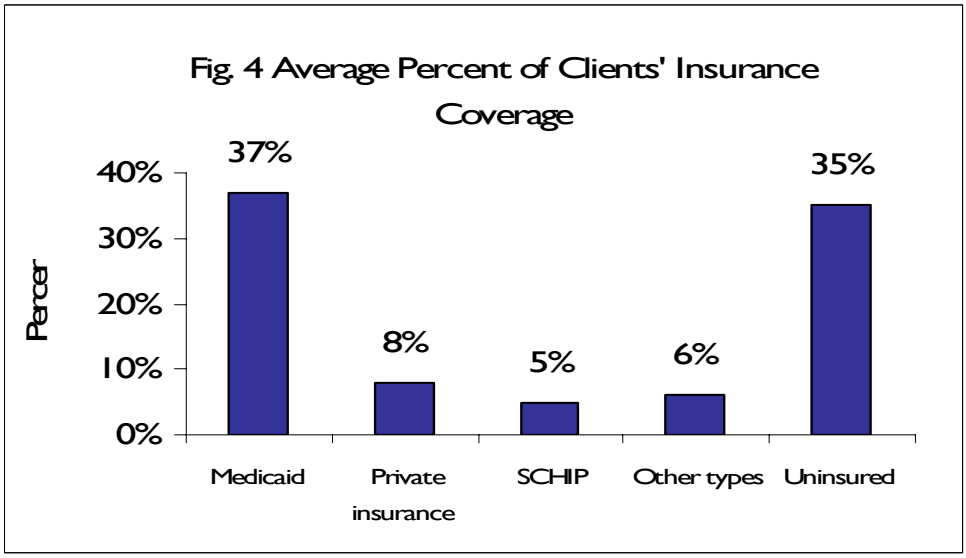
Percent estimates based on responding sites

Childcare

One of the 23 respondents reported having childcare at their site. This site noted that childcare was, "*Informal— staff will babysit while the patient is being served.*"

Affordability

The greatest percentage of clients seen at responding sites in the past year were covered by Medicaid or were uninsured. Figure 4 shows the average percent of clients covered by different types of insurance from the 19 sites with available data who provide services for a fee. Medicare was listed as one of the 'other types of insurance' by eight sites.



Percent estimates based on responding sites

Quality

Coordinated Care

Eighty-three percent of responding sites (N=19) reported that care at their site was coordinated for clients for services from different agencies in the community (i.e. coordination of client's care between the site and referral sites, identification of community resources and monitoring of services accessed). Specific comments made by sites providing care coordination for services from different agencies in the community were varied and are listed below. Comments included reference to specific employee positions responsible for coordinating care, models and systems used for coordination, modes of communication and types of resources and services needing coordination.

- *Face to face contact, email, phone calls*
- *Specialty services at local clinics or [Tribal] service unit. Trying to connect patients with providers that can care for them, such as putting in touch with [Tribal] service unit.*
- *We arrange for follow-ups with specialists, obtain prior authorizations, etc*
- *Through a public health/case management model and agreements with mainstream providers*
- *We are an Outreach and Referral Program*
- *Work closely with Medicaid, WIC, OBGYNs, Department of Health and Headstart programs*
- *Home visitor acts as case manager*
- *Hospitals and clinics notify the Agency's case management to assist with ancillary services*
- *Community health representatives assist in coordination*
- *Medi-Cal managed care*
- *If needing OB specialist, clients are referred and follow through is checked*
- *Work closely with health department a few blocks away for WIC, STDs, and support from state health department. Safety-net clinics refer all to us for prenatal care. [University] Medical OB residents deliver babies, outreach support staff – native*
- *We have a referral coordinator who tracks and monitors referrals for clients in Medical Department*
- *For our providers needs around the client going and coming to the hospital or care home, etc. We use RNs and a referral coordinator to case-manage these needs. Similarly, we have staff that work with clients on insurance issues, housing, the justice system, etc. Share clients for example.*
- *Referrals to other departments or to outside providers/specialists, MCIR vaccine database*
- *Monthly case management meetings*
- *Phone & fax information*
- *Through staffing referrals*

Seventy-eight percent of responding sites (N=18) reported that care within their site was coordinated for clients (i.e. coordination of client's care between departments within site, provider meetings to discuss prenatal patients, identification of resources and monitoring of services accessed). Specific comments made by those sites that provide care coordination within their site are listed below. Comments focused on meetings between staff from different

departments ranging from an informal to a weekly basis. Specific staff and departments, involved in coordination, and certain clients for whom care is coordinated were also noted.

- *Informal meeting (only 10 staff total)*
- *Coordination of care between mental/behavioral health & clinic departments*
- *We see patients for first prenatal and then help them get to an OB*
- *Weekly clinical meetings that include all provider staff*
- *Provider meetings occasionally, referral/benefits coordinator, nursing*
- *Depression screening team has membership from two clinical departments*
- *All staff works as a team from front desk, billing, transportation, nursing and medical*
- *Case management, case study*
- *Formal referral process and verbal/written progress reports*
- *Prenatal meetings [weekly] with Prenatal team*
- *Weekly provider meetings, monthly medical staff meetings, weekly departmental meetings, monthly all-staff ongoing informal meetings*
- *Two times per month - prenatal providers meet to review cases. Four times per month - diabetes providers (medical, dental, health education, fitness, nutrition) meet to review high risk clients*
- *Within the clinic, this is done well using emails or staff meeting time between our buildings. It's done using emails and some one will call for a meeting with a certain group of people. It's better than it was, but still needs work (we don't have electronic medical records).*
- *Weekly case management meetings for diabetes clients, referrals to other departments or to outside providers/specialists, MCIR vaccine database*
- *Monthly provider meetings*
- *Weekly case conferences*
- *Regular meetings with staff are designed to keep everyone informed. There are CHR's for the patient population*

<u>Culturally Specific Programs</u>

Forty-six percent of responding sites (N=11) have culturally specific MICH programs for AI/AN (i.e. traditional diet, cradleboard classes, AI/AN group leaders, etc). Comments provided included:

- *Not specifically, if requested, treatment is customized to meet the request of the patient if applicable.*
- *Registered Dietitian provides information on traditional diet*
- *AI/AN Group Leaders and Indian Parenting Classes*
- *Offered in cooperation with [local American Indian organization]*
- *Limited to traditional diet demonstrations, support groups for men and women*
- *Diabetes prevention, [area specific programming], traditional direct counseling/classes, HIV testing/counseling - counselors native, Two-spirit group*
- *We have offered these and do still, primarily at our residential and outpatient treatment centers and our family wellness program that offers parenting classes and also classes to reconnect adolescents with their traditional values. Our diabetes and women's wellness programs at the clinic bring these types of activities into their groups as well.*

- *Parenting workshops with elders teaching skills to youth, diabetes self-management, traditional medicine classes, monthly elder appointments, monthly talking circle and lodge, summer programs: pink shawl, yellow choker, drum socials and screenings, diet and dance for exercise, elder-youth conference*
- *Positive Indian parenting, healthful diet counseling in a AI/AN cultural context for childbirth, labor & delivery & breastfeeding*
- *We have a cradleboard program described in Indian Country. We also recommend traditional diets*

Children/Youth with Special Health Care Needs

Sixty-four percent (N=14) of responding sites reported serving children with special healthcare needs (CSHCN). Two sites responded "Don't know", one of which noted they were not aware of the capacity for serving children with special needs. Three sites reported a total of 250 AI/AN CSHCN seen in the past year. Six sites commented that the number of children/youth with special healthcare needs was unavailable. Descriptions of care for CSHCN included:

- *Case management and referrals*
- *We see premature babies and those with disabilities*
- *Rarely, one Family Nurse Practitioner on provider staff*
- *Primarily through referral and working to have parents hooked into the mainstream system*
- *Fetal Alcohol Syndrome and effects*
- *Children's health is assessed quarterly to annually by specialists that we follow through on their plan of action based on the child's/family's needs*
- *Prematurity, developmental delay*
- *Primary care only*
- *Some routine care, but referred for specialty care*
- *Pediatrician, child mental health*
- *Childcare is provided at out outpatient and residential treatment center and family wellness programs.*
- *[Local] children's mental health program is family centered with ongoing team meetings*
- *We also refer to local and regional services*

Family Centered Care

Of those sites who provide care to CSHCN, 75% (N=12) reported that the care for CSHCN was "family-centered" (i.e. the child's provider has a strong partnership with the family, where they work together for the child; the provider listens to patient and family perspectives and choices; the provider communicates and shares complete information with the patient and family; and patients or families actively participate in care and decision-making at the level they choose). Specific descriptions of family-centered care offered were:

- *As much as possible given family dynamics*
- *This has not occurred with the few children we have seen*
- *Through family consultation and a multi-disciplinary team*
- *We always strive to involve the whole family (parents, siblings, grandparents, aunts/uncles) and school/childcare providers in the plan of care*

- *Family-centered [care] is the foundation of the care our clinic provides*
- *[Medical Director] usually involved in this*
- *We provide a 7-week curriculum called [family skills training program] to AI/AN families at a minimum of twice a year*
- *The lengthy [children's mental health program] assessment identifies family needs and the care plan incorporates family strengths. The family team meetings provide ongoing feedback & coordination of services.*

Quality Assurance and Effectiveness Outcomes

Survey participants were asked to describe any quality assurance or quality improvement activities in place for MICH services at their site. Two sites noted that the question was "not applicable" to them and four sites said they have "none", "none at this time" or "none specific to MICH". The responses for sites that reported activities are listed below. These comments included multiple methods for QA and QI such as committees and groups specifically responsible for this task, meetings among these groups as well as other clinic departments, and various tracking systems and chart reviews for specific services.

- *Quarterly [Quality Assurance(QA)] meetings for all issues*
- *Yearly QA Questionnaire. Recalls for missed Well Child checks or immunization appointments. Quarterly Health Advisory Board meetings and monthly Medical Staff meetings.*
- *When we had an OB, tracking immunizations, well-women exams, STDs, etc*
- *Surveys, monitoring*
- *[Weekly] meetings help focus on problem areas, discussion then follows about solutions*
- *Included in [Quality Improvement(QI)], [Government Performance and Results Act (GPRA)], chart reviews*
- *QA group that meets together for the agency … at the clinic we are working with the hospital, so we can provide prenatal care for 24 weeks prior to referring to them. And we are setting the new moms' 2nd prenatal appointment up with the maternal case manager that works for us.*
- *Review of all prenatal charts two times a month*
- *Weekly case management meetings for diabetes (DM) patients, annual DM chart audit for Special Diabetes Program for Indians grant, internal DM chart audits PRN, MCIR chart audits for immunizations, GPRA chart audits annually, assessment of summer youth program participants and BMI trend over years*
- *[Local children's mental health program] has an evaluation committee the medical department maintains primary care QA & QI monitoring & reporting of services*
- *Services are reviewed by the QI committee*

Effectiveness Measures

Survey participants were also asked about the outcomes they use to measure the effectiveness of their MICH programs. Four sites stated that the question was "not applicable", one site stated they have "none", two sites stated they have "no specific outcome measures" or "none – work toward GPRA indicators; no specific outcomes for MICH programs" and one site was unsure. The responses for the seven sites that reported outcome measures are as follows:

- *We refer and follow-up*

- *We track numbers through [Urban Indian Health Program Common Reporting Requirements (UCRRs)]*
- *Screening for immunization rates; family planning services*
- *Surveys, success stories*
- *Mandatory timely and complete immunizations and well-child visits*
- *GPRA, [Uniform Data System (UDS)]*
- *We look at the number of children receiving their well-child checks and immunizations. […] a challenge is that some of our patients have Kaiser Insurance for example and come to us only when they can't get in with their regular provider and come in for a same day appointment.*
- *Comprehensive perinatal services program (CPSP) monitor high risk indicators, WIC, dental services, psycho-social assessment, breastfeeding & contraception plans, insure car seat for baby*
- *[GPRA standards for childhood immunizations and referrals for PAP and mammograms. Plans to incorporate improvements with childhood BMI screening at every office visit for height and weight, annual counseling with eligible women at regular office visits for Fetal Alcohol Syndrome (FAS) prevention, annual screening for domestic violence/intimate partner violence]*

Summary and Recommendations

The findings of this capacity needs assessment highlight current areas of strength as well as areas of need among participating UIHO. The majority of sites provide onsite and/or referral for pregnancy and infant health services such as immunizations, well-child visits and parenting support. However, between 22% and 35% of sites do not offer or refer clients for maternity case management, childbirth classes, home visits/public health nurse visits and SIDS counseling. Greater than 17% of sites do not offer or refer clients for newborn screening and lactation support. The need for pregnancy and infant health services is also reflected in the large number of sites reporting provider/service shortages and shortages of resources/funding for MICH services. The need for OBGYN providers and services was a theme repeated throughout the survey and limited funding for an OB provider was also reported as a barrier to care for pregnant women.

The large number of sites not offering or referring clients for pregnancy and infant health care, in addition to the documented shortages of providers/services and resources/funding for this type of care, is concerning given the data on the urban AI/AN population, which show high rates of factors related to poor birth outcomes and infant mortality. In particular, the high rates of SIDS in the urban AI/AN population lend greater necessity to the provision of counseling and home visits.

Nearly 35% of sites do not offer or refer patients for abortion services. Beyond the stated shortages of OBGYN providers, it is unclear whether the lack of abortion provision is related to restrictions in public funding. Specifically, in accordance with the Hyde Amendment, the IHS cannot provide abortion services to Indian women except in the case of rape, incest, or life endangerment[18].

The need for dental and prenatal dental care providers was mentioned specifically by site representatives and was reported as an unmet need by both clients and providers. A high percentage of participating sites also do not offer or refer clients for prenatal and pediatric dental services. The scientific data in this area has revealed a high prevalence and severity of dental disease in the AI/AN population nationwide, five times the U.S. average rate of untreated dental caries for children age 2-4.[19] Additionally, AI/AN have not experienced the dramatic decline in dental caries as seen in U.S. children in general. In fact, trends over time suggest increasing caries rates in AI/AN preschool children served by IHS, urban and tribal dental clinics.[20] This has resulted in an overwhelming demand on the resources available to provide care.[21] Associations have been found between oral infections and diabetes, heart disease and stroke, and adverse pregnancy outcomes, hence the impact of oral infections on the AI/AN population may be even more dramatic than currently measured. In order to improve access to care for AI/AN populations, resources to pay and reimburse for dental care should be addressed.[22]

Traditional health services are provided by 65% of participating sites, but there may be room for growth with regard to cultural programming at UIHO for AI/AN. Greater than half of the clients seen in the past year were AI/AN, yet less than half of participating sites reported having culturally-specific MICH programs for AI/AN. One site pointed out that they experience shortages of culturally-competent providers and services for the uninsured. In a recently published preliminary survey of Indian health facilities conducted in 2004, lack of funding was cited as a root cause for lack of staff and time to develop and implement cultural training programs for health care professionals working in Indian health care.[23] A staff person from an UIHO, which was categorized as not having considered creating a cultural training program, was cited as believing the task was impossible because of the number of different tribes served and the challenge of creating a program focused on all tribes. This demonstrates the challenges of UIHO to serve the needs of an extremely diverse population, with typically hundreds of tribes represented in urban areas.

Most sites provide transportation assistance to their sites, but only one of the participating sites offer childcare on an informal basis. The impact of environmental factors, such as transportation and child care, on missed clinic appointments has been examined. The inability to obtain transport was found to impede appointment keeping, and patients who had to arrange for child care in order to attend the clinic were more likely to miss their appointments.[24] The need for child care and transportation was mentioned expressly by clients and may be an important barrier to the provision of health services for UIHO.

Most sites have some mechanism for clients and providers to report unmet need. Mechanisms for communicating need are critical for health programs to most effectively serve their client population. Sites might consider using reporting mechanisms for providers to offer specific insight into how to address difficulty with provider recruitment (specifically with OBGYN and dental care providers) and lack of provider stability that was mentioned by survey participants. In a nationwide survey of work environment perceptions and dentists' salaries in community health centers, while salary was not found to be a significant factor, years of experience, freedom of professional judgment, altruistic motivation, importance placed on loan repayment and amount of administrative time allowed were associated significantly with career change intentions.[25] Periodic salary surveys, as well as standardized exit surveys for dentists who do

leave, were suggested by authors as potentially effective methods for monitoring factors associated with recruitment and retention as well as reasons for dissatisfaction of dentists.

The large number of sites providing coordinated care both within their site and between their site and other agencies highlights the work that the UIHO are doing to ensure a high quality of care even when resources for providing onsite services may be lacking. Case management and referral to "specialty" services appears to be a priority for participating sites. Additionally, nearly all sites providing care to children with special health care needs reported that care was family-centered. Many of the comments provided by UIHO illustrate best practices that could be culminated and shared among all UIHO.

A variety of quality assurance/improvement activities were described, but outcomes used to measure the effectiveness of MICH programs were not consistent across sites. One site alluded to issues such as the lack of continuity of care or insurance coverage in a comment regarding client's use of the clinic when they cannot get appointments from their usual source of care. These issues may create challenges in the reliability of some outcome measures.

As of May 2006, health care facilities operated and run by the Urban Indian Health Program are required to report their Government Performance and Results Act (GPRA) clinical performance measures to IHS and Congress on a quarterly basis. Reported information must include a data supported audit trail that can be verified and validated by the Office of Management and Budget. While there are limitations to GPRA data, the reporting requirements aim to provide a system-wide assessment of quality patient care. Government Performance and Results Act clinical measures are reported in the Prevention and Treatment categories; some of the 17 measures are: quality of care for patients with diabetes, cancer screening, immunizations, domestic violence screening, Fetal Alcohol Syndrome prevention, childhood weight control, tobacco cessation, Pap smear and mammogram rates and depression screening.[26]

Limitations

There are data collection issues in any public health needs assessment. First, the evidence upon which many intervention programs are based is continually changing; this requires a degree of flexibility within the public health system as new information is learned through research. Second, while the Institute of Medicine is calling for new ways to measure and evaluate outcomes, community indicators are difficult to measure across the board, given the vast range of variation in health care and indicators of social, psychosocial, socioeconomic, historical, and political situations. Additionally, separating the complex effects of these indicators on each other is a challenging task. Third, it is often difficult to accurately measure the outcomes deemed important, such as when prenatal care is begun, or the effects of breastfeeding on infants, in a way that minimizes or negates confounding influences.[27]

A limitation of this survey was the self-reported answers with no objective confirmation for accuracy. Related to this, the accessibility of information to participants in filling out the survey may have varied depending on the infrastructure of the individual UIHO; some of the UIHO may not have the ability to gather the data that was asked of them in the survey because of the lack of electronic records databases etc.

In 2006, we invited 34 sites to participate. In the first year, 56% (N=19) completed a survey and one site partially responded by telephone (Round I total response rate=59%). In the second year of the survey, an additional four sites responded and the partial response was completed via survey for a total of 24 participating sites (Round II Total response rate=71%). It should be noted that the differing timing of participation might have introduced slight differences between sites responding for different years, but this is not expected to have a great impact on interpretation of the findings. The timing of the Round I MICH Capacity Needs Assessment survey administration (beginning in April 2006) may have been part of the reason for the initially low response rate. In February 2006, President Bush submitted to the Congress a proposal to eliminate funding for the urban Indian health program in the Indian Health Service FY-2007 budget plan. This proposed budget forced many organizations to re-prioritize their activities in order to respond to the crisis. Decreased/threatened federal funding was also noted specifically by one site as a resource/funding shortage.

In looking at the results, it is important to take into consideration the diversity of the UIHO. To begin, the areas considered "urban" vary—for example, Billings, MT, and New York, NY, are both cities that offer services to urban AI/AN, though naturally there will be differences in their situations, given their geographic locations and the characteristics of those locations. The people who use the services vary in tribal affiliation, socioeconomic status, and so on. Services, too, vary from location to location, in that some health organizations operate perhaps with a staff of two nurses who provide referrals for diabetes care, whereas other organizations might provide full services including dental care and cultural programming. Urban Indian Health Organizations all have different systems for patient management, such as electronic records; others may not have the institutional resources to create or maintain records on who they refer and for what services. Additionally, what information is gathered is not uniform, so the determination of an accurate denominator for the population was difficult.

Moreover, some of the UIHO do not provide MICH-specific services per se, and expressed uncertainty about whether it was appropriate for them to fill-out the survey; though this did provide an indication of their MICH service capacity. Thus, given the differences in the survey population, many of the questions we asked in our survey may not have been appropriate, which was reflected in some of the missing or "not applicable" responses.

Although shortages of resources and funding for UIHO were assessed with this survey, other financial factors related to the decision by the UIHO to have or not have programs focused on maternal and child health, were not specifically asked. For example, the status of individual UIHO as Federally Qualified Health Centers (FQHC) or recipients of Federal Title V MCH Block Grant Funds, Federal Title XIX (Medicaid) Title X (Family Planning) Funds, State General Funds and other funds, all have an impact on the reimbursement rates of the UIHO and the availability of services for maternal, infant and child populations. The accessibility of these funds also varies from state to state and year to year, and may depend on the size of the population served, according to vital statistics records. As noted by a representative from one site, "The challenge is to figure out how to maximize these services given our high risk population and high no show rates." Future assessments focused specifically on these topics might provide insight into the critical issues of financial stability, sustainability and capacity of the UIHO to provide MICH services.

Conclusion

Urban AI/AN women, infant, child and youth populations experience substantial health disparities compared to the general population.[28] Castor et al describe disparities in rates of infant mortality, SIDS, and premature births among urban AI/AN compared to the general population in the same areas.[29] Approximately 160,000 AI/AN residing in urban areas are served by 34 independent urban Indian heath organizations (UIHO).[30] The UIHO provide critical services to AI/AN women, infant, child and youth populations. The findings of this capacity needs assessment may be used internally by UIHO to help appropriately allocate resources, design effective programs and guide further examinations of the impact of services. Information from the survey, including gaps in services, may also be used to supplement health status indicators to further justify the need for the urban Indian health program.

Following the implementation of HRSA's four steps of capacity assessment and the matching of population needs and organizational capacity, the next step is for organizations to set priorities which address the needs that they are capable of working on; moreover, the "priorities must be linked to concrete measures."[31] Setting priorities involves framing them—should they be broad or narrow, should new programs be developed or should existing ones be strengthened. The process of priority setting also includes "convening a body of stakeholders," to determine the priority-selecting criteria and consult on priority choices.[32]

Maternal and Child Health Advisory Council

It is important to involve community stakeholders as well as other MCH-related organizations in the process of priority making, and translating these priorities into action.[33] To this end, in August 2006 the UIHI developed a Maternal and Child Health Advisory Council who is charged with advising and supporting the UIHI MCH surveillance in various ways including, review of data, guidance with reports, and input regarding direction and priorities. The council is comprised of primary care clinicians, researchers, public health professionals, UIHO representatives, community members and others. The results of the MICH CA have been shared with this MCH Advisory Council for review. The MCH Advisory Council includes a majority of AI/AN participants, so that the voice of this population is the guiding force of priority setting*.

*For more information about the MCH Advisory Council, please contact Shira Rutman at the Urban Indian Health Institute 206-812-3030.

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Appendix A

National Performance Measures
HRSA, MCH Services
Title V Block Grant Program

1) The percent of newborns who are screened and confirmed with condition(s) mandated by their State sponsored newborn screening programs (e.g. phenylketonuria and hemoglobinopathies) who receive appropriate follow up as defined by their State.
2) The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN survey)
3) The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey)
4) The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. (CSHCN Survey)
5) Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. (CSHCN Survey)
6) The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life. (CSHCN Survey)
7) Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.
8) The rate of birth (per 1,000) for teenagers aged 15 through 17 years. *
9) Percent of third grade children who have received protective sealants on at least one permanent molar tooth.
10) The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children. *
11) Percentage of mothers who breastfeed their infants at hospital discharge. *
12) Percentage of newborns who have been screened for hearing before hospital discharge.
13) Percent of children without health insurance.
14) Percent of potentially Medicaid-eligible children who have received a service paid by the Medicaid Program.
15) The percent of very low birth weight infants among all live births. *
16) The rate (per 100,000) of suicide deaths among youths aged 15 through 19. *
17) Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.
18) Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester. *

* Those chosen by UIHI as MCH indicators.
HRSA. Maternal and Child Health Services Title V Block Grant Program: Guidance and Forms for the Title V Application/Annual Report, May 31, 2003. ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf

Date: _____
ID#: _____

Urban American Indian/Alaska Native (AI/AN) Maternal, Infant and Child Health (MICH) Capacity Assessment Questionnaire 2005–06

Introduction

This survey asks about your maternal infant and child health program. We are interested in learning about the services that your organization provides and how they are used by your clients. By taking this survey, you will help us to better provide technical assistance to your site. This information may also ultimately help to improve the services and programs for the maternal, infant, child and adolescent groups in your community.

This survey is voluntary. If there are questions that you feel uncomfortable answering, you may refuse to answer them by selecting "Don't know/Refused." Risks are minimal and include the potential breach of identity of survey respondents (i.e. someone else may figure out who answered the survey at a site). However, a majority of questions on the survey ask publicly available information about type and availability of services offered at your site.

If you don't know the answer to some of the questions in the survey, we encourage you to fill the survey out as best as you can, and seek further information from others in your organization, if possible. If it is not possible to find particular pieces of information, we encourage you to provide us with your best estimate.

This survey will take about 10 minutes to complete.

Section 1. Demographics

1. Please enter the total number of clients seen at your site in the past year: _____
2. Please enter the number of AI/AN clients seen at your site in the past year: _____
3. Please enter the number of AI/AN MICH clients in each age group seen at your site in the past year:
    a. Number of AI/AN women (age 18-44)_____
    b. Number of AI/AN infants (age<1)_____
    c. Number of AI/AN children/adolescents/youth (age 1-22) _____
    d. Number of AI/AN children/youth with special health care needs_____

Section 2. Services

4. Please check all type(s) of MICH services that you offer:

Sexual Health

a. Contraception

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

b. Pregnancy testing

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

c. Abortion services

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

d. STD testing

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

e. HIV testing and counseling

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

Pregnancy and Infant Health

f. Prenatal care

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

g. Maternity case management

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

h. Childbirth classes

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

i. Newborn screening

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

j. Early hearing loss screening

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

k. Lead screening

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

l. Lactation support

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

m. Immunizations

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

n. Well child visit

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

o. Home visits/public health nurse visits

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

p. Parenting support

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

q. Prenatal dental

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

r. Pediatric dental

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

Women's Health

s. Preconception or interconception care

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

t. Well women's exam

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

u. Nutrition

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

v. Dental

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

Mental Health/Social Services

w. SIDS counseling

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

x. Domestic violence counseling

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

y. Mental health counseling

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

z. Smoking cessation

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

aa. Substance use counseling

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

bb. WIC/food assistance/food bank

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

cc. Other (specify) _____

General

dd. Laboratory

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

ee. X-Ray

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

ff. Pharmacy

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

gg. Traditional health

❑Onsite ❑Referral ❑Both onsite and referral ❑Do not offer/refer

Please Describe:

_____

hh. Other (specify) _____

Section 3. Accessibility

5. What is the average length of time that clients have to wait to get an appointment of any type? (number of days) _____
6. Are there shortages of providers or services?

   ❑Yes ❑No ❑Don't know ❑Refused

   If yes, please describe:_____
7. Are there shortages in resources/funding for providing MICH services?

   ❑Yes ❑No ❑Don't know ❑Refused

   If yes, please describe:_____
8. Do you provide transportation assistance to your site?

   ❑Yes ❑No ❑Don't know ❑Refused

   If yes, please check which type:
   ____Bus coupons
   ____Taxi voucher
   ____Shuttle bus/van
   ____Other (describe):_____
9. Do you offer childcare at your site?

   ❑Yes ❑No ❑Don't know ❑Refused

10. Is there a mechanism for **clients** to report any unmet need for services or difficulty accessing the services they need?

❑Yes ❑No ❑Don't know ❑Refused

If yes, please describe any unmet needs **reported by clients**:

_____

11. Is there a mechanism for **providers** to report clients' unmet need for services or difficulty accessing services?

❑Yes ❑No ❑Don't know ❑Refused

If yes, please describe any unmet need **reported by providers**:

_____

Section 4. Quality

12. Is care coordinated **within** your site (i.e. coordination of client's care between departments **within your clinic**, provider meetings to discuss prenatal patients, identify resources and monitor services accessed)?

❑Yes ❑No ❑Don't know ❑Refused

If yes, please describe how this happens:

_____

_____

13. Is care coordinated for clients at your site for services from **different agencies** in the community (i.e. coordination of client's care **between your site and referral sites**, identify community resources and monitor services accessed)?

❑Yes ❑No ❑Don't know ❑Refused

If yes, please describe how this happens:

_____

_____

14. Do you have culturally specific MICH programs for AI/AN (i.e. traditional diet, cradleboard classes, AI/AN group leaders, etc.)?

❑Yes ❑No ❑Don't know ❑Refused

Please elaborate:

_____

_____

15. Do you provide care to children with special health care needs?

❑Yes ❑No ❑Don't know ❑Refused

If yes, please describe:

_____

_____

15a. If yes, is care for children with special health care needs "family-centered" (i.e. the child's provider has a strong partnership with the family, where they work together for the child; the provider listens to patient and family perspectives and choices; the provider communicates and shares complete information with the patient and family; and patients or families actively participate in care and decision-making at the level they choose)?

❑Yes ❑No ❑Don't know ❑Refused

If yes, please describe:

_____

_____

16. What is the average waiting time to be seen in the clinic? (number of minutes)

_____

17. Please describe any quality assurance or quality improvement activities in place for MICH services at your site:

_____

_____

18. What are the outcomes used to measure the effectiveness of your MICH programs?

_____

_____

Section 5. Affordability

19. What is the health insurance status of AI/AN clients seen at your clinic? Please enter the percent covered by each type.

a. ____% Medicaid
b. ____% Private
c. ____% Uninsured
d. ____% State Children's Health Insurance Program (SCHIP)
e. ____% Other (specify):_____

20. Do out-of-pocket costs pose a barrier to care for children, women, or pregnant women at your site?

❑Yes ❑No ❑Don't know ❑Refused

If yes, please comment:

_____

THANK YOU FOR YOUR TIME!

Appendix B

Contact Information

You have finished the survey.

Please provide us with your contact information, so that we can send you a Thank You for your participation and contact you for clarification with responses if needed.

Primary Respondent's Contact Information:

Name: _____
Title: _____
Organization: _____
Address: _____
City: _____
State: _____
Zip: _____
Telephone: _____
Fax: _____
Email: _____

Please provide information on other respondents who assisted in completing the survey (if any):

Other Respondent #1:
Name: _____
Title: _____
Phone: _____
Email: _____

Other Respondent #2:
Name: _____
Title: _____
Phone: _____
Email: _____

Appendix C

UIHO Service Area Counties and States

Health Organization Service Area	Counties	State
First Nations Community Health Source Albuquerque, NM UIHO	Bernalillo	New Mexico
Bakersfield American Indian Health Project Bakersfield, CA UIHO	Kern	California
Indian Health Board of Billings, Inc. Billings, MT UIHO	Big Horn, Yellowstone	Montana
North American Indian Alliance Butte, MT UIHO	Silver Bow	Montana
American Indian Health Services of Chicago, Inc. Chicago, IL UIHO	Cook	Illinois
Urban Inter-Tribal Center Dallas, TX UIHO	Collin, Dallas, Denton, Ellis, Hood, Johnson, Kaufman, Parker, Rockwall, Tarrant, Wise	Texas
Denver Indian Health and Family Services Denver, CO UIHO	Adams, Arapahoe, Boulder, Denver, Douglas, Gilpin, Jefferson	Colorado
American Indian Health and Family Services Detroit, MI UIHO	Genesee, Ingham, Kent, Wayne	Michigan
Native Americans for Community Action Flagstaff, AZ UIHO	Coconino	Arizona
Fresno Indian Health Association Fresno, CA UIHO	Fresno, Madera, Tulare	California
Indian Family Health Center Great Falls, MT UIHO	Cascade	Montana
United Amerindian Health Center, Inc. Green Bay, WI UIHO	Brown, Door	Wisconsin
Helena Indian Alliance Helena, MT UIHO	Jefferson, Lewis & Clark	Montana
North American Indian Center of Boston, Inc. Jamaica Plain, MA UIHO	Suffolk, Middlese, Norfolk, Plymouth	Massachusetts
Nebraska Urban Indian Health Coalition Lincoln, NE UIHO	Douglas, Lancaster, Sarpy, Washington, NE, Woodbury, IA	Nebraska
United American Indian Involvement Inc Los Angeles, CA UIHO	Los Angeles	California
Gerald L. Ignace Indian Health Center, Inc. Milwaukee, WI UIHO	Milwaukee, Waukesha	Wisconsin

Appendix C

Indian Health Board of Minneapolis Minneapolis, MN UIHO	Hennepin, Ramsey	Minnesota
Missoula Indian Center Missoula, MT UIHO	Missoula	Montana
American Indian Community House New York, NY UIHO	Bronx, Essex, Kings, Nassau, New York, Queens, Richmond, Westchester	New York
Native American Health Center Oakland, CA UIHO	Alameda, Contra Costa, Marin, San Francisco, San Mateo	California
Native American Community Health Center Phoenix, AZ UIHO	Maricopa	Arizona
South Dakota Urban Indian Health, Inc. Pierre, SD UIHO	Brown, Hughes, Minnehaha, Stanley	South Dakota
Native American Rehabilitation Assoc. of the NW, Inc. Portland, OR UIHO	Clackamas, Multnomah, Washington, OR, Clark,WA	Oregon
Nevada Urban Indian, Inc. Reno, NV UIHO	Carson City, Churchill, Douglas, Storey, Washoe	Nevada
Sacramento Native American Heath Center, Inc. Sacramento, CA UIHO	Sacramento	California
Indian Walk-In Center Salt Lake, UT UIHO	Davis, Salt Lake, Tooele, Utah, Weber	Utah
San Diego American Indian Health Center San Diego, CA UIHO	San Diego	California
Indian Health Center of Santa Clara Valley, Inc San Jose, CA UIHO	Santa Clara	California
American Indian Health & Services Santa Barbara, CA UIHO	San Luis Obispo, Santa Barbara, Ventura	California
Seattle Indian Health Board Seattle, WA UIHO	King	Washington
N.A.T.I.V.E. Project Spokane, WA UIHO	Spokane	Washington
Tucson Indian Center Tucson, AZ UIHO	Pima	Arizona
Hunter Health Clinic Wichita, KS UIHO	Butler, Reno, Sedgwick, Sumner	Kansas

UIHI
Urban Indian Health Institute