

Culture, Service and Success:

A Profile of Urban Indian Health Organization
Programming to Address Cardiovascular Disease

August 2011





The mission of the Urban Indian Health Institute is to support the health and well-being of Urban Indian communities through information, scientific inquiry and technology.



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TABLE OF CONTENTS

1	EXECUTIVE SUMMARY
3	INTRODUCTION
6	METHODS
7	RESULTS
	PROFILES OF SUCCESS
8	Indian Health Board of Minneapolis
10	Denver Indian Health and Family Services
12	The N.A.T.I.V.E. Project
14	Hunter Health Clinic
15	DISCUSSION
16	RECOMMENDATIONS
18	APPENDIX A: SURVEY INSTRUMENT
20	APPENDIX B: INTERVIEW QUESTIONS

Please contact the Urban Indian Health Institute with your comments: info@uihi.org or 206-812-3030. You can also fill out the form on page 21 with comments or questions.

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EXECUTIVE SUMMARY

Introduction

The purpose of this report is to provide a description of the cardiovascular disease (CVD) programming at urban Indian health organizations (UIHO) to address the growing burden of CVD in urban American Indian and Alaska Native (AI/AN) communities. In particular, the findings presented here include approaches that make CVD programs successful in urban AI/AN communities. Lastly, the recommendations provide suggestions for building on existing UIHO infrastructure and assets to expand the depth and breadth of programming available to urban AI/AN.

Methods

Information presented here was collected from February through May 2011 from surveys and key informant interviews of participating UIHO directors and program staff. The main topics of the data collection included: (1) CVD services offered by UIHOs, (2) incorporation of AI/AN culture in CVD services, (3) coordination of care, (4) resources used by UIHO for program design and implementation and (5) successful strategies, achievements and stories highlighting promising practices in urban AI/AN communities.

Results

Of the 32 currently operating UIHOs and one satellite site invited to participate, 26 (79%) completed the survey in 2011. Additionally, four key informant interviews were also conducted during this period.

Highlights of this report's findings include:

- The CVD services offered with the most widespread availability included nutrition education, screening services and medication management. The least offered services are comprehensive CVD programs.
- The majority of UIHOs incorporate AI/AN culture into services.
- Approximately three-fourths of UIHOs report coordinating care internally with their organization's departments or externally with referral sites or community partners.
- Two of the top three resources used by UIHOs to inform their programs were drawn from evidence-based sources (National programs/models and literature). A majority of UIHOs also draw on input from staff and are responsive to their clients and community members.
- Specific activities or program features that supported program successes included: group and family centered activities; enhancing access to services; offering incentives; knowledgeable AI/AN staff; coordinating patient care; and having key leadership support or an organizational champion for the program.

Discussion

Approaches used by UIHOs in preventing, treating and managing CVD demonstrate innovation, adaptability and an ability to enact meaningful services with limited resources. Successful approaches that work towards achieving health equity for AI/ANs exhibit the following characteristics:

- Providing appropriate care at the appropriate time (i.e., multidisciplinary teamwork and internal/external coordination of care that treats the whole person);
- Knowledge of the unique health and social needs of urban AI/ANs;
- Using a holistic approach to wellness that focuses on the whole person including the involvement of traditional healers and understanding the role of family and community in an individual's health.

Recommendations

Based on UIHO survey responses and interview data, the following recommendations are made to strengthen programs in urban AI/AN communities to reduce morbidity and mortality due to CVD and work toward achieving equity in the overall health of urban AI/AN people:

- Identify and increase the availability of designated funding, program models and training opportunities to better address the CVD burden in urban AI/AN communities;
- Build on the strengths of the UIHOs' existing data collection infrastructures to expand evaluation of programs and build an evidence base specific to urban AI/ANs;
- Leverage limited resources by building additional or stronger partnerships with allied health organizations, governmental health organizations and academic institutions.

INTRODUCTION

Once rare among American Indians and Alaska Natives, cardiovascular diseases are now the leading causes of death for AI/ANs. Heart disease risk factors such as diabetes and hypertension are now more prevalent among AI/ANs than nearly any other group in the United States, and this prevalence continues to rise. CVD mortality rates for middle-aged AI/ANs are now up to 40% worse than for the general population (U.S. Department of Health and Human Services, Indian Health Services, 2009). The subsistence lifestyle and traditional foods that once protected AI/ANs against heart disease have been replaced by physical and political environments leading to sedentary lifestyles and unhealthy diets that promote heart disease and diabetes.

Cardiovascular diseases are not only major sources of death they are also sources of considerable illness, disability and healthcare costs. These diseases, which include heart attacks, heart failure and strokes among many other conditions, are largely preventable. Diabetes mellitus, smoking, high cholesterol and hypertension are all major risk factors contributing to the development of clinically significant CVD. The remarkable strides in clinical treatment of CVD in recent years are currently threatened by the continued rise of diabetes and high blood pressure not only for AI/ANs but for the general population as well.

Addressing CVD and its risk factors is central to progressing toward eliminating health disparities. The Indian Health Service (IHS), along with research and academic institutions, helped identify and address the “rising tide” of CVD with notable successes. However, these efforts were launched largely among tribal or reservation communities in rural areas with access to Indian Health Service support, missing the majority of AI/ANs who reside in urban areas. For all AI/ANs to achieve health equity, best practices for the prevention, treatment and management of CVD specifically designed for urban AI/ANs must also be disseminated among the urban Indian health organizations that serve this often resource-strapped population.

In this new report, sponsored by the Office of Minority Health, the Urban Indian Health Institute (UIHI) has collected and summarized successful models for promoting CVD health among UIHOs, which can now be shared between these programs to promote health equity for the population. Information on the range of available CVD programs for urban AI/ANs has never before been compiled. This report identifies several elements associated with success and innovation at UIHOs that have implemented systematic CVD programs. Such information is vitally important, particularly as the future portends a growing and long-term epidemic of CVD.



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Urban American Indians and Alaska Natives

American Indians and Alaska Natives living in urban areas are a diverse and growing population. Over the past four decades, AI/ANs have increasingly relocated from rural communities and reservations into urban centers. According to the 2000 Census, this population now makes up more than 67% of all AI/ANs living in the United States. However, the needs of the nation’s urban AI/ANs have been so infrequently addressed or recognized that the population has been referred to as “invisible” (Urban Indian Health Commission, 2007).

Urban AI/ANs are a very diverse group and include members, or descendents of members, of many different tribes. Represented tribes may or may not be federally recognized, and individuals may or may not have historical, cultural or religious ties to their tribal communities. The population as a whole is highly mobile; individuals may travel back and forth between their tribal communities or reservations on a regular basis. Urban AI/ANs are also generally spread out within the urban center instead of localized within one or two neighborhoods and thus are often not seen or recognized by the wider population.

Urban Indian Health Organizations

Established through Congress under Title V of the Indian Health Care Improvement Act in 1976 and permanently re-authorized by the 111th congress, UIHOs are independent, not-for-profit entities with urban AI/AN majority boards of directors. Nationwide there are 34 UIHOs with service areas encompassing 100 select urban counties in 19 states across the country (see map below). UIHO range in size and services from small referral sites to comprehensive medical and dental clinics that serve the wider community. Often seen as centers for community and cultural activities, UIHOs offer AI/ANs living in these urban areas a place where they can receive health information and services in a culturally appropriate manner. UIHOs serve a vital role in assuring access to primary medical care for the low-income urban AI/AN population, yet receive approximately only 1% of the overall IHS budget.



The Urban Indian Health Institute

In 2000, the Urban Indian Health Institute was established as a division of the Seattle Indian Health Board to study and document the striking health disparities effecting the urban American Indian and Alaska Native population. The UIHI is one of 12 tribal epidemiology centers and the only organization providing surveillance, research and analysis of data focused specifically on the nationwide urban AI/AN population. The mission of UIHI is to support the health and well-being of urban AI/AN communities through information, scientific inquiry and technology.

Health Equity Project

Responding to the persistent inequities in health outcomes among urban AI/ANs, the UIHI launched the Health Equity Project in 2010. With support from the U.S. Office of Minority Health, the project is focused on identifying and disseminating culturally appropriate successful models of care in urban AI/AN communities to prevent and reduce disease. The Health Equity project focuses on three diseases identified as critical focus areas for health improvement in urban AI/AN communities: cardiovascular disease, depression and a third community-identified disease topic. Additionally, the Health Equity Project will provide tools, trainings, information and will facilitate partnerships to support UIHOs in delivering best practices or components of best practices to their clients. The importance of documenting and recognizing these effective culturally-targeted programs in reducing morbidity and mortality in minority communities is essential in order to achieve Healthy People 2020 goals and to realize the overall outcome of health equity for all.

The information in this report was gathered through a survey and interviews with Executive Directors and program staff of UIHOs. In the coming years, we will continue to collaborate with select UIHOs to strengthen programs addressing CVD and highlight approaches to services that can reduce the burden of disease in our communities. We hope this report will serve as a source of ideas and inspiration, as well as outline the strengths and opportunities in future CVD related programming. It is essential that best and promising practices, as well as the techniques and challenges encountered in implementing them, are shared among those working with urban AI/AN communities. Healthy People 2020 goals for cardiovascular disease and the elimination of health disparities cannot be achieved without the dissemination of such practices.

For this project we have used the following definitions that are based on The Community Guide to Preventive Services (Centers for Disease Control and Prevention, 2011) and the Indian Health Service Online Search, Consultation and Reporting System (Indian Health Service, n.d.):

Evidence-based: Program activities or models based on rigorous scientific evidence demonstrating statistically significant effectiveness.

Best practice: Program activities or models for which effectiveness in achieving specified goals or objectives has been demonstrated or suggested through formal evaluations.

Promising practice: Innovative program activities or models that appear to achieve the program goals/objectives and have the potential to be implemented in other locations but lack systematic evaluation and review.

METHODS

Survey

In February of 2011, an introduction to the project and invitation to participate in the survey was emailed to the Executive Director and select program staff of the 32 currently operating urban Indian health organizations and one satellite clinic. The email included instructions for participating in the survey over the phone, online or by completing a paper version that could be downloaded and printed out from the email attachment. During the four weeks following the initial emailing, Health Equity Project staff conducted two follow-up phone calls and one follow-up email to those who had yet to respond. If at any time the Director or program staff declined to participate in the survey, no further attempts were made.

In addition to learning about the type and availability of CVD programs offered by UIHOs, we also wanted to learn about the extent of evidence-based and best practices in use at UIHOs. We identified the following as important elements in an evidence-based or best practice for urban AI/ANs:

1. Coordination of care;
2. Influences on program design and implementation;
3. Outcomes and successes;
4. Incorporation of elements of AI/AN culture, traditions and perceptions of health.

Survey data were entered into a database, and any responses that were contradictory either within a survey itself or between respondents for a given site were clarified via email with the site. Not all questions were answered within each completed survey; the number of respondents for each question is included with the reported results. Percentages represent the number of respondents for each individual question as the denominator.

Survey Limitations

In the development of the survey, we strived to use clear language and examples or definitions to provide clarification of the intent of the survey item. However, differential interpretation of the survey items and language likely influenced the responses chosen. This limitation may have affected the type and availability of services reported, the types of activities thought to qualify as incorporating AI/AN culture and the relatively low percentage of respondents identifying advisory boards as influencing programming.

Key Informant Interviews

In addition to the survey, we also wanted to share more in-depth accounts of how select programs were developed, are maintained and the successes they have achieved. Based on survey responses, select UIHO Executive Directors and program staff were invited to participate in an approximately one hour-long interview. The interviews were conducted with program staff over the phone in May and June of 2011. Each organization was emailed a draft of the success story and was given two weeks to provide edits, comments or feedback. These comments were incorporated into the final draft, which was returned to the participating sites for approval from program staff, Executive Directors and any relevant partners prior to this publication. Programs highlighted throughout this report are characterized by successful outreach efforts and innovative strategies aimed at reducing or preventing cardiovascular disease. These programs are but a few examples of the excellent work ongoing at each urban Indian health organization across the country.

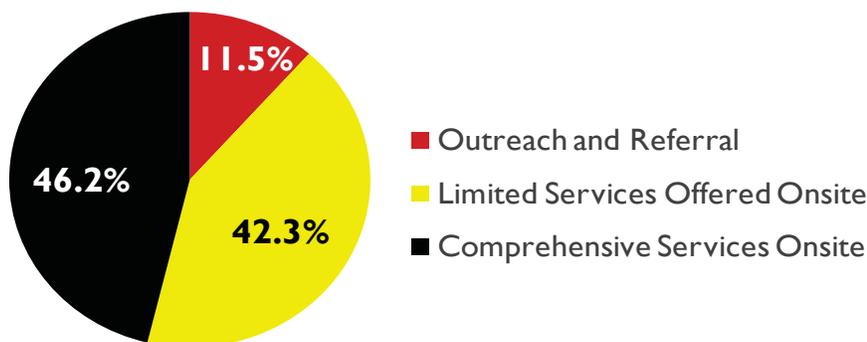
RESULTS

Out of the 32 and one satellite site currently operating UIHOs, 26 (79%) responded to the survey. Respondents were a variety of Executive Directors, Program Directors, Medical Directors, Health Educators and other program staff.

Organization Type

The UIHOs range in scope of services from outreach and referral to comprehensive ambulatory care centers. The figure to the right shows the distribution of respondents by organization type. The following definitions were used to characterize organization type:

Figure 1. Organization Type



Outreach and Referral Site refers to organizations that provide education services and outreach to engage and connect urban AI/ANs to healthcare services. These agencies do not directly provide clinical care.

Limited Services Site refers to organizations that provide some clinical care onsite, as well as education and referrals to other community providers.

Comprehensive Services Site refers to organizations that provide a full range of medical and in some cases dental services.

Cardiovascular Disease Services

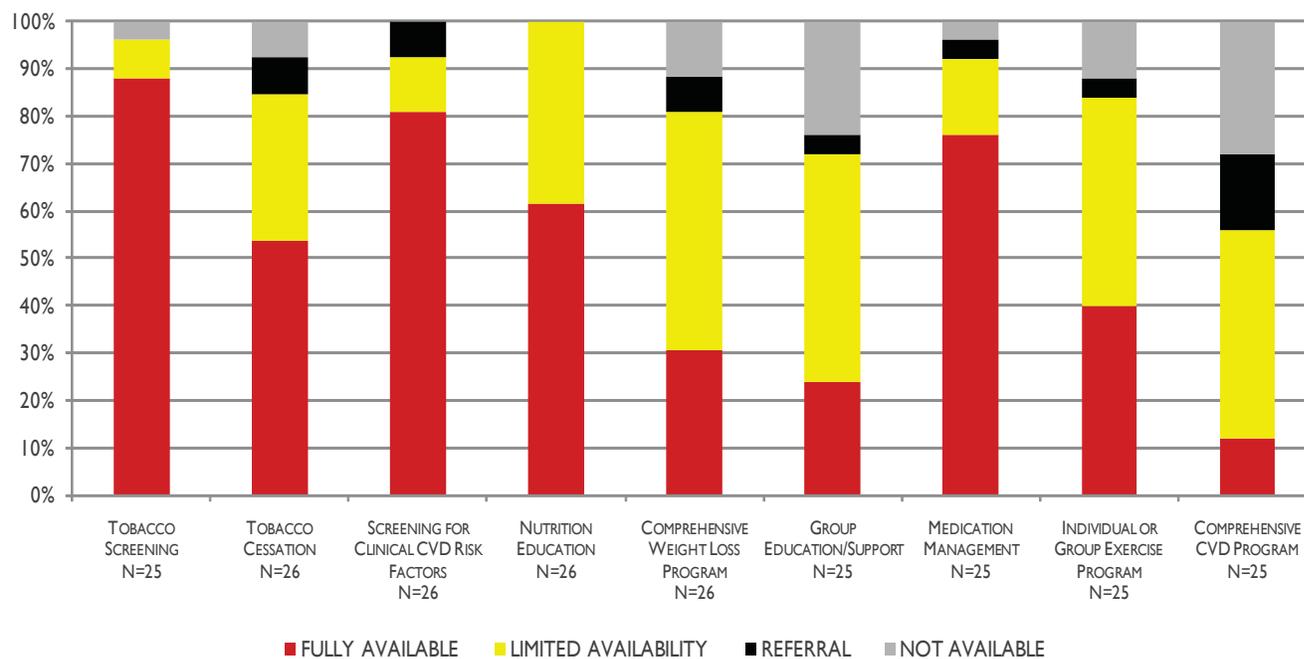
In addition to the type of CVD related services offered, the level of availability is also an important aspect of patient access to care. The following definitions were provided to characterize the availability of CVD care:

Fully Available means that services are available with little to no restrictions. For example: There is no limit on the number of people who can access services; services are available on most days; or there is financial assistance available.

Limited Availability means that services are available but with some restrictions. For example: There are a limited number of people who can access services; services are available on limited number of days; or economic barriers exist, like high co-pays.

Referral means that patients are provided with information and/or support to access services that the organization does not provide directly.

Screening services and medication management have widespread availability across participating UIHO. Screening activities are essential for identifying patients who are at risk and providing early interventions. With early intervention, it is possible to prevent the development of disease, extend the number of healthy years and improve quality of life.

Table 1: Type and Availability of CVD Related Services

Services to assist in developing and maintaining healthy lifestyles are also widespread through the network of UIHOs as evidenced by the response that all sites are offering nutrition education, many are offering comprehensive weight loss programs and physical activity or exercise opportunities. More difficult to implement, especially with limited resources, are comprehensive CVD programs that can span the multiple risk factors, lifestyles and clinical needs of CVD.

SUCCESS STORY

INDIAN HEALTH BOARD OF MINNEAPOLIS (IHB)

The Minneapolis experience provides an example of clinic staff adapting evidence-based curriculum to meet the needs and interests of their client base. Adaption of the curriculum content, logistical support of transportation and reminder calls as well as other supportive structures, such as social networks and smoking cessation resources, have contributed to the success of the IHB Healthy Heart Project.

While the overall mortality rate for Minnesotans is lower than that of the US population overall, the Minnesota Department of Health (MDH) - Office of Minority and Multicultural Health identified striking disparities in a number of health outcomes for certain groups, including cardiovascular disease in American Indians and Alaska Natives. To support community-based responses to close the gap in health status, the MDH established the Eliminating Health Disparities Initiative. It was through this initiative that the IHB received funding to develop and implement the Healthy Heart Project in 2010.

The Healthy Heart Project consists of a ten-week series of classes held at two community housing locations. Classes are based on the Honoring the Gift of Heart Health curriculum and cover CVD risk factors, signs and symptoms of a heart attack, healthy meals and recipes, reading food labels, smoking cessation, and physical activity. With prevention of heart disease as the main goal, all American Indians aged 18 and over are welcome to participate, even those without current risk factors for CVD.

Participant recruitment into the Healthy Heart Project occurs at community events and powwows. At these events, the program coordinator conducts blood pressure screenings for interested participants. This presents IHB with the opportunity to teach community members about the importance of controlling blood pressure as well as to provide information about participation in the Healthy Heart Project.

Ten (38.5%) respondents described a variety of other CVD related services offered at their organization including: diabetes activities, community outreach and education, strategic partnerships and coalitions, participation in or hosting health fairs, case management, Wellness Programs, having workout/fitness centers onsite, stress management classes, walking clubs, talking circles, and offering or incorporating the National Heart, Lung, and Blood Institute's curriculum Honoring the Gift of Heart Health.

Incorporating AI/AN Culture

The majority (88%) of survey respondents are incorporating AI/AN culture into their services, either directly or through referral. Incorporation of AI/AN culture can happen in many ways and is not limited to traditional medicine but can include such activities as talking circles or traditional dancing to promote physical activity.

Culturally tailored interventions are shown to be significantly more effective in improving health outcomes and providing accepted programs (Keyserling et al, 2002; Darling et al, 2004; Philis-Tsimikas et al, 2004). Cultural competency in the delivery of care improves its acceptability and therefore effectiveness (Kagawa-Singer, 1997).

Incorporation of cultural practices and traditions into programming is also important for addressing social isolation and supporting cultural identification among urban AI/ANs. Social isolation – a combined isolation from resources, support networks, job networks, and cultural and spiritual groups – increases stress and stress related health behaviors that negatively impact health outcomes (Brunner & Marmot, 2001).

The health educator conducting these classes found the curriculum to be too basic for participants and has adapted it to include more health information as well as more interactive components, such as navigating a grocery store. Additionally, participants expressed the desire to learn CPR, which is not covered in the original curriculum, so she has become a certified CPR instructor to pass this knowledge onto participants. Anonymous feedback and suggestions are solicited from participants at the end of the class series so that the class can continue to adapt to the interests and needs of the community.

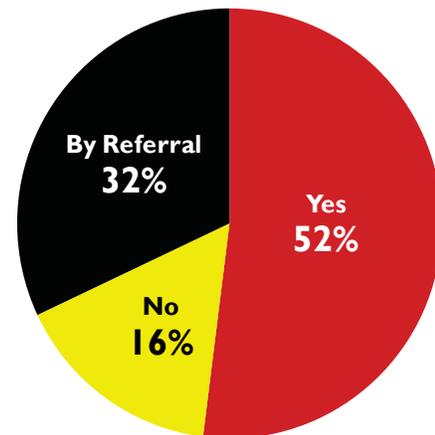
Clinical measures, including cholesterol, blood pressure, and BMI as well as health behaviors such as smoking and diet are collected by the health educator at the beginning of the program and are repeated at 3 and 6 months to assess the impact of class participation. The most recent assessment showed that program participants have decreased their cholesterol, blood pressure and are quitting smoking. Additionally, participants are sharing the daily changes they are making to live healthier lives, like drinking water instead of sodas.

IHB staff have found that providing transportation to and from the clinic and making reminder calls the day of classes has greatly helped the program achieve these successes. The group classes support the development of social networks among participants, as well as creating peer accountability for healthy behaviors. An additional resource IHB can refer participants in the battle against heart disease and stroke is the Mashkiki Waakaigan Pharmacy, which provides free medications, such as nicotine gum, patches, Wellbutrin or Chantix, to enrolled American Indians to support smoking cessation.

Training on the honoring the Gift of Heart Health curriculum from the University of Colorado, Denver and on smoking cessation from the Mayo Clinic helped to prepare the health educator to address the needs of participants.

For more information about IHB Healthy Heart Project contact Maria Krisch at mkrisch@ihb-mpls.org or (612)-721-9803.

Figure 2: Incorporation of AI/AN Culture into CVD Services

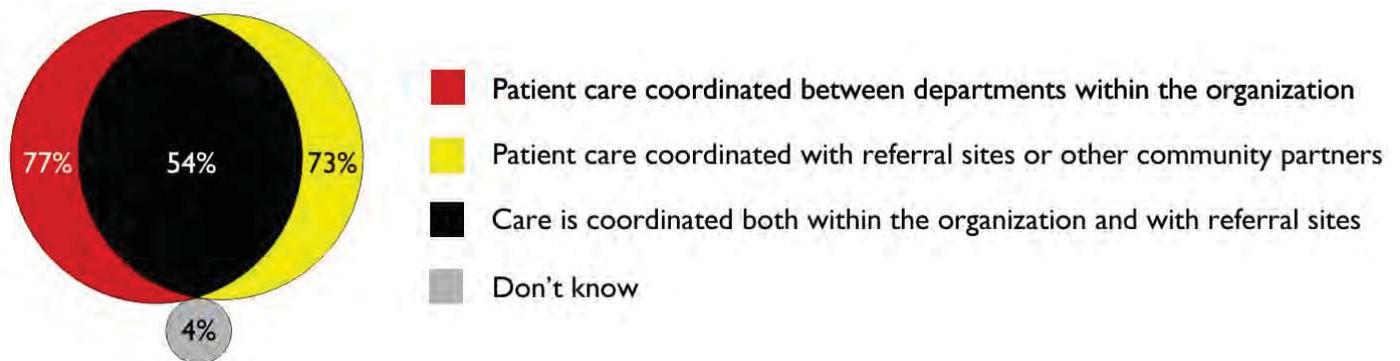


Coordination of Care

Coordination of care is critical for improving patient access to comprehensive services and realizing improvements in health outcomes. A collaborative, on-going process, coordination of care assures smooth transitions between systems and services for patients (Haggerty et al, 2003). Not only is coordination of care an opportunity to increase patient satisfaction, but it helps support patient compliance (Ouwens et al., 2004; Kobb et al., 2003; Coleman & Berenson, 2004). By providing more and effective opportunities for clinical improvement, care coordination is considered an indicator of quality care.

Coordination of care is especially appropriate for the management of chronic diseases, such as CVD. As shown in **Figure 3**, UIHOs are working both across clinic departments as well as with other community resources to ensure patients receive comprehensive care.

Figure 3: Coordination of Care



Influences on Program Design

Public health and healthcare funding sources are requiring that grantees implement evidence-based or best practice interventions as a stipulation for funding. This poses challenges for UIHOs since most evidence-based practices were not developed or tested in the AI/AN population, let alone the urban AI/AN population.

SUCCESS STORY

DENVER INDIAN HEALTH AND FAMILY SERVICES, INC. (DIHFS)

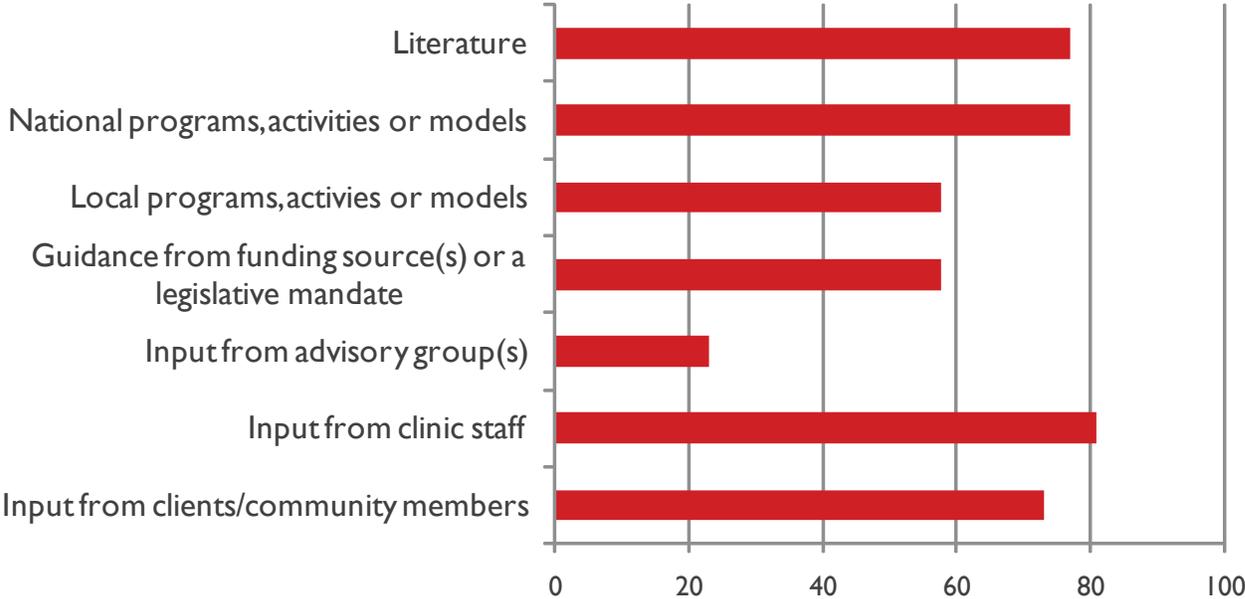
Characterized by clear communication and mutual respect, the Denver experience provides an example of how strategic partnerships can expand a clinic's scope of services and support data collection and reporting efforts specific to urban American Indians and Alaska Natives.

Two years ago, in a climate of scarce resources, a partnership formed between the Centers for American Indian and Alaska Native Health at the University of Colorado at Denver (UCD) and DIHFS to conduct the Fresh Insights Toward Health (FIT Health) pilot study. As community-based participatory research becomes recognized as the standard in identifying and advancing community health needs and innovative culturally appropriate health promotion interventions, large research institutions are increasingly looking to community expertise and partnerships. In a climate of chronically scarce resources, DIHFS recognized this partnership as an opportunity to expand the health education services available to their patients. Prior to beginning study activities, DIHFS consulted with an advocate for study participants at UCD for guidance and advice on partnering with an academic institution and information on their rights as a research partner. This process helped DIHFS assess that the partnership was a good fit for their agency and one that they wanted to pursue.

FIT Health is a pilot study assessing two approaches to decreasing the risk for diabetes and cardiovascular disease and has been operating at DIHFS for almost two years. DIHFS staff assist in participant recruitment, which is an important element for collaboration, as community members who are diagnosed with diabetes during the eligibility screening process are referred to

Such evidence-based practices may not be culturally appropriate and therefore, ineffective in the urban AI/AN population. The survey found that UIHOs are drawing from many resources and key stakeholders to inform the design and implementation of their programs. This suggests the importance of expanding the definition of evidence-based care in AI/AN communities to include other types of evidence including drawing on the lived experiences of clients, staff and community members.

Table 2: Percent of Respondents Using Source for Program Design and Implementation



Only two (7.7%) respondents did not know what influenced the design of programs, choice of activities or implementation. Three (11.5%) respondents identified other factors that influenced program design and implementation including: the American Heart Association, Indian Health Service contract/funding and practice.

clinic services rather than the study. Study participants take part in ‘Honoring the Gift of Heart Health’ classes and received a Wii Fit Plus™ as an incentive and to encourage physical activity at home. Health status is measured through BMI, blood pressure, lipid panels, and blood glucose. These classes and health measurements are conducted by case managers and health educators that are employed by UCD, but spend several days a week at the clinic and have developed relationships with clinic staff and patients.

Throughout the partnership, a positive relationship has been maintained through open lines of communication. The Principle Investigator of the study meets periodically with clinic staff to ensure that study activities are not a burden on them or negatively impacting patient flow. These meetings also offer an opportunity for clinic staff to share their expertise with the University such as information on cultural norms and strategies appropriate to the community for enhancing recruitment and retention. These meetings - in addition to attending powwows, DIHFS health fairs and other community events - have helped UCD establish a presence in the community and build a trusting relationship with both the clinic staff and patients. Findings from the study are expected in the fall.

This partnership has opened the door to other research opportunities, including an oral health project with the local Children’s Hospital, and has further developed DIHF’s internal capacity and planning for future research activities. For example, DIHFS’s Board of Directors is developing a data sharing agreement for use in future research project partnerships. They are also developing policies to guide the types and number of research projects the clinic participates in to ensure that all studies and projects support the clinic’s mission and priorities.

For more information about the DIHFS’s partnership with UCD, contact Adrienne Maddux at (303) 953-6618 or amaddux@dihs.org.

What Makes a Program Work?

To clarify program components and share lessons learned in the process of achieving program goals, UIHOs were asked to identify specific activities or factors that support success. Responses to this question are summarized in the categories below.

Groups and Families – Across sites, respondents identified group activities and the involvement of families as a key to success. **Group and family centered** activities are not only an effective way to expand the reach of informational and therapeutic interventions, they also provide an opportunity for peer support that encourages maintenance of newly acquired skills and creates accountability for individuals trying to reach their individual health goals. Additionally, group and family activities allow participants to develop interpersonal relationships that support overall wellness.

Access - Many respondents noted the importance of the **availability** of the services themselves; patients being able to get into the clinic and programs as well as being able to interact with providers, such as dietitians and case managers. Beyond having services, providing **transportation** to the clinic or other sites of service was noted as critical in engaging patients who would not otherwise be able to participate or receive care. Offering programming during **non-conventional hours**, such as weekends and evenings, improves patient access to these services as they tend to be more convenient for clients and do not compete with other priorities.

Incentives – Providing **incentives**, including food, t-shirts, and small prizes, has proven effective for many respondents in engaging, retaining and motivating participants. Incentives are not limited to material goods. It also incentivizes activities when they are **fun and interactive**, such as providing a healthy meal experience or family game nights.

Staffing – Survey respondents attributed specific qualities in their staff as well as program success. Increasing staff capacity through **training and certification**, as well as staff providing client **follow-up** and **community outreach** were also noted as vital activities.

Coordination of care – Some respondents reported **integrating services** between departments and

SUCCESS STORY

N.A.T.I.V.E. PROJECT (Spokane, Washington)

Exemplifying a traditional and holistic approach to health, the N.A.T.I.V.E Project's Native Community Wellness Program demonstrates the importance of the family-centered approach to health. This innovative strategy incorporates health promotion activities into community gatherings.

Since the organization's creation in 1989, the N.A.T.I.V.E. Project has strived to engage youth through after school programming. Recognizing the importance of including the entire family and community to create an environment of wellness, the N.A.T.I.V.E Project expanded these activities into a Native Community Wellness Program six years ago. Through a partnership with the local school district, the N.A.T.I.V.E Project was able to secure two gyms and classroom space to host the Native Community Wellness Program two nights a week throughout the school year.

The Native Community Wellness Program offers a multitude of classes and activities including: adult basketball, Zumba, youth fitness, healthy cooking classes, beading, a walking club, Salish language classes and a gang violence prevention program. Each month the Native Community Wellness Program focuses on a new health topic relevant to their community, such as diabetes and cardiovascular disease. The variety of programming provides engaging, interactive activities that promote physical and nutritional health, enrich social and familial bonds and connect the community with cultural traditions. Participant accomplishments in these activities are honored with prizes at an end-of-the-year Awards Dinner.

having **continuity of care** as a key to successful care. A few respondents identified how **teamwork** and **communication** between providers has supported their successes.

Support – While support for clients in making behavior and lifestyle changes to improve their health is important, respondents also noted how essential having the support of clinic and **community leadership** is to programming. Having a **champion** within the organization helps to prioritize a program or activity and make sure it has the needed resources.

Achievements

Success can be defined in many ways. UIHOs were asked to share successes from CVD programming in an effort to understand what success looks like and the achievements these programs are reaching. Responses to these questions are categorized into the themes below.

Participant Successes – Survey respondents reported a wide variety of what patient level successes look like. Many respondents report improvements in **clinical measures**, such as lipids, weight and blood pressure. Additionally, respondents have tracked patient achievement in meeting **individualized goals**, and have seen and heard of **lifestyle and behavior changes**. A number of important, non-clinical successes were also identified as outcomes from CVD-related activities such as enhancing relationships within families as well as **social bonds** and **relationship building**.

Participation – A number of sites identified increased **participation** in CVD activities and **retention** of these participants as a marker of success. Participation and retention not only speak to these programs responding to a community need but also reflect **patient satisfaction** with the programming. Many sites conduct client surveys and the findings reinforce patient satisfaction with programming.

Program Success – It is important to recognize success on the organizational level as well as the participant level. The ability of sites to provide and maintain programming was reported by survey respondents, as well as increasing staff **capacity** through trainings and certifications. Additionally, the flexibility of the programs to respond to the needs and preferences of their communities was a key component of the programmatic successes.

While funding is always a challenge, through creativity and resourcefulness the Native Community Wellness Program has been able to garner support through grants and partnerships. For example, local partnerships with the Spokane School District, Washington State University Extension Program and the local public health department have not only provided funding and space to conduct the program but also brought in expert volunteers and allowed for collaboration on a “Healthy Me” curriculum. The N.A.T.I.V.E Project does not only pursue traditional grants to fund the program but also has received funding from such organizations as Regents Blue Cross/Blue Shield that share the common goal of improving health outcomes. Pursuit of diverse funding sources has greatly contributed to the N.A.T.I.V.E Project’s ability to provide consistent programming.

Native Community Wellness Program success has grown over the years, with 60 to 125 participants at each event and 1700 unique visitors throughout the year. The N.A.T.I.V.E Project’s ability to be flexible and adjust programming to reflect the health and social needs of the community has greatly contributed to this success. Additionally, program staff contribute much of the success to the consistent nature of the program, rarely canceling programs even in extreme weather, which has gained respect throughout the community.

For more information about the N.A.T.I.V.E Project’s Indian Community Wellness Program contact Candy Jackson at (509) 483-7535 or cjackson@nativeproject.org or Tara Dowd at (509) 483-7535 or tdowd@nativeproject.org.

SUCCESS STORY

HUNTER HEALTH CLINIC (Wichita, Kansas)

The health care environment, as well as patient care, is increasingly complex. Managing patient information and developing informatics systems is a formidable task for any community clinic, but Electronic Health Records (EHR) is one development that can help providers and patients alike plot a course through these complexities. EHR can help improve coordination of care by allowing multiple components of the patients care, including administrative and billing, clinical and laboratory, pharmacological, medical and social history, and visit notes, to be integrated into one system. With a complex chronic condition such as cardiovascular disease, EHR can help multiple clinicians provide comprehensive care. The Hunter Health Clinic has supported a progressive transition to EHR since March 2010. The decision to use the Indian Health Service Resource and Patient Management System (RPMS) Electronic Health Record was easy for Hunter Health; there was no cost for licensing, software, installation or IT support as it is all provided through IHS. The only cost was the network infrastructure.

Before implementation, an overview of EHR and how its technology can enhance services was discussed at several staff meetings. This discussion and acknowledgement of the challenges that would be associated with the adoption of EHR helped to garner support, buy-in and commitment to EHR from all staff members. Hunter Health staff visited other clinics to learn from their experiences implementing the same EHR system to ensure success in the transition.

Hunter Health Clinic took a number of steps to ensure the transition to EHR was as smooth as possible. Staff attended three days of training that provided an opportunity to become familiar with the system using scenarios that were realistic. During the early stages of implementing the EHR, Hunter Health Clinic allowed twice as much time for appointments to allow providers time to navigate the EHR system. IT support remains on-site to provide additional training or trouble shooting as necessary.

An EHR Committee of various Hunter Health staff members meets on a regular basis to discuss the implementation process and address any issues that arise. The EHR Committee works with IT support to continuously make updates and adjustments to the system to better meet the needs and preferences of staff. Staff meetings provide additional opportunities to explore the strengths and weaknesses of the system, and share tips that can make the system easier to navigate. Staff training and involvement in the EHR Committee has increased their internal capacity. Some logistical barriers, such as small room size, still present a challenge in the full implementation of EHR into clinic work flow.

As adjustments are made to the system, and staff get more comfortable with the technology, it has become easier to maximize the potential of the system. While there was some initial hesitance among staff, they have found that the EHR can help them be more efficient in patient visits. With a mobile population, the EHR and a patient's medical history follows them between satellite locations eliminating the need for duplicating work, improving accuracy and patient safety. The EHR has enhanced Hunter Health's ability to track and follow patients, provide appropriate referrals and strengthened communication among staff. In the future, the enhanced data collection capacity of EHR can support evaluation of services.

The EHR makes refilling of prescriptions especially easy for both providers and patients. This has streamlined care, increasing patient and provider satisfaction. Another benefit of the EHR has been the system's ability to provide a print out of the patient's medical history and visit summary. Hunter Health encourages patients to keep this record with them as a way to improve care across multiple settings. This practice is especially useful for patients with limited English proficiency.

For more information about Hunter Health Clinic's Electronic Health Records contact Michelle Base at (316)-262-3611 or mbase@hunterhealthclinic.org.

DISCUSSION

CVD programming is an opportunity to impact the multiple modifiable risk factors that are highly interconnected to some of the most pressing health issues facing urban AI/ANs and overall well-being. It is the leadership demonstrated at all levels of staffing at the network of UIHOs that can address the grave health disparities in CVD burdening AI/AN communities. Their innovative thinking and commitment to their communities is an essential component of the services provided at the UIHOs. Programs are drawing upon both traditional knowledge and emerging science to create appropriate services for the urban AI/AN population. A key characteristic of CVD programming is the blending of culturally relevant strategies with data driven information. Many programs are monitoring their clients' satisfaction with services and adjusting program components in order to best meet the needs of the population they serve. UIHOs are uniquely positioned to prevent and manage cardiovascular disease and play critical social and public health roles, as outlined below.

Appropriate care at the appropriate time

Achieving health equity for urban AI/ANs is based in part on receiving timely, culturally-relevant and comprehensive care prior to the onset of disease or illness. Comprehensive care requires treatment of the whole person. Social, physical and spiritual care works to prevent illness and elevates overall health. Coordination of care is a critical component of the work of the UIHOs. It is evident from the survey and key informant interviews that UIHOs are working with multidisciplinary teams both within the organization and other community providers to ensure comprehensive, coordinated services are available to urban AI/ANs.

The network of UIHOs provide essential public health functions for the urban AI/AN community. Where possible, UIHOs have developed comprehensive CVD programs that are community driven, incorporating components from national models, evidence from literature and direction from community members into their program services. The UIHOs are best positioned to screen and treat urban AI/ANs for CVD and related risks because of their knowledge of the community and ability to not only address the health care needs, but also the cultural and social needs of the urban AI/AN population.

Knowledge of and communication with urban AI/AN community

Survey and key informant interview findings demonstrate that UIHOs are staffed with health professionals that possess a commitment to serving the community's unique health and social needs. UIHO staff work to identify appropriate communication channels for their client population and host community events where health messaging and promotion take place. Many UIHOs survey their client population periodically to assess local health priorities, and all are required to track client satisfaction on an annual basis. Through this existing data collection infrastructure, information may be used to evaluate program reach, expand outreach efforts, or provide overall client satisfaction and monitoring. No other health authority maintains this kind of local knowledge for urban AI/AN communities.

Holistic approach to wellness

Through this survey and key informant interviews, UIHOs have demonstrated they are uniquely suited to provide culturally relevant public health practice, both clinical and social. Many UIHOs act as a "health home" for their clients, providing truly integrated services that are whole-body focused. Many survey responses note the essential role of family in overall health and tailor their health promotion and disease prevention efforts accordingly. As evidenced by survey results, the majority of UIHOs (88%) are incorporating traditional concepts of health and wellness into their clinical services including providing access to traditional health practitioners. This kind of integrated care stands alone in the health care system.

RECOMMENDATIONS

UIHOs require additional financial and institutional resources to meet the CVD needs of their community. A major barrier for most, if not all, UIHOs is the lack of resources available for this essential work. Resources available to prevent and treat CVD in urban AI/ANs remain disproportionate to the population distribution. Despite the fact that a majority of AI/AN people reside in urban areas, the federal government's Indian Health Service appropriates only 1% of its funding to urban Indian health. These limitations restrict not only the staffing and availability of programs but also the ability to evaluate the work being done. With access to resources and training, UIHOs can build on their unique strengths to incorporate evaluation components beyond their current data collection capacity.

It is clear from this survey and key informant interviews that clinics are utilizing client suggestions and preferences gathered through satisfaction surveys to improve the desirability and acceptability of programming. However, UIHO programs need support to build upon their data collection infrastructure and capacity to more comprehensively evaluate their program outcomes. Enhanced evaluation of programs will help establish the evidence-base for effective services for urban AI/AN patients.

UIHOs must build stronger partnerships with state and local health departments, academic institutions and allied health organizations. One way to leverage limited resources is through strategic partnerships. Many UIHOs have built strategic partnerships to address gaps in resources. This may include participation in a community coalition addressing heart disease, contracts with local health departments or involvement with academic institutions conducting community-based participatory research. Partnerships can offer access to trainings and skill building through knowledge exchange. Partnerships between UIHOs also provide opportunities for peer learning; while often geographically distant, the communities served and barriers to care may have similarities. Partnerships create opportunities for dissemination of information and innovations that can support UIHOs in serving their communities.

What is evident through this report is that the groundwork to prevent and treat CVD is in place. The infrastructure for data collection exists at all UIHOs, and programs would benefit from additional training in areas of data collection, analysis and use. Each UIHO is currently collecting and reporting clinical data on an annual basis, but opportunities remain for putting that data to use.

In order to build upon the foundation of CVD programming, UIHOs must receive additional resources to strengthen the scope of evaluation efforts. These resources are not limited to financial support and include resources to build internal capacity and reach. Assessing program impact requires skill building and training among UIHO staff to design and implement comprehensive evaluations. As more evidence regarding the effectiveness of programming becomes available as a result of evaluation efforts it will be essential to facilitate venues and modes of dissemination to share best practices. Many of these capacity-building resources can come from strategic partnerships with allied organizations.

Strengthened evaluation to increase understanding of practices in urban AI/AN communities, strategic partnerships to leverage resources and skills, and the dissemination of best practices are essential in working toward health equity and achieving Healthy People 2020 goals.

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APPENDIX A:

SURVEY INSTRUMENT

ADDRESSING CARDIOVASCULAR DISEASE AND BEHAVIORAL HEALTH: A SURVEY OF URBAN INDIAN HEALTH ORGANIZATIONS

This survey asks about the cardiovascular disease (CVD) and behavioral health programs and services your organization provides. By taking this survey, you will help us understand what is being done to help reduce the burden of CVD and depression in our community. This information will be used to inform a report highlighting the best practices among urban AI/AN and lay the groundwork to strengthen the services available to your clients.

This survey is voluntary and will take about 10-20 minutes to complete. All responses will remain confidential; however we may contact you to request clarification or further information.

If you don't know the answer to some of the questions in the survey, we encourage you to answer as best as you can and seek further information from others in your organization.

1. Please tell us a little about yourself.
 - Name:
 - Job Title:
 - Contact information:
 - a. Phone:
 - b. E-mail:
 - City:
2. What is the name of your organization?
3. Please select the option that best describes your organization:
 - Outreach and referral agency
 - Limited direct services provided on-site
 - Comprehensive direct services provided on-site

This section is related to services you CURRENTLY provide in prevention, treatment or management of cardiovascular disease (CVD).

4. For each of the following CVD related questions, please check if the service is **fully available** at your organization, your organization has **limited availability**, your organization provides referral or **not available**.

Fully Available means that they are available with little to no restrictions. Examples might be that there is no limit on number of people who can access service; service is available on most days; or that there is financial assistance available.

Limited Availability means that they are available but with some restrictions. Examples are: there are limited number of people who can access service; services is available on limited number of days; or economic barriers exist, like high co-pays.

Referral means that you provide patients with information and/or support to access services your organization does not provide directly.

	Fully Available	Limited Availability	Referral	Not available
Screening for tobacco use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tobacco cessation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Screening for clinical CVD risk factors (such as blood pressure, lipids, obesity, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutrition education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comprehensive weight loss program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Group education/support group for those living with or at risk for CVD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Individual or group physical activity/exercise program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comprehensive CVD program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1. Please describe any activities or services your organization engages in to prevent or treat CVD or its risk factors *not listed above*.
2. Do any of your CVD related programs/interventions incorporate elements of American Indian/ Alaska Native culture? For example, do you offer traditional healing?
 - Yes No By referral
3. Are the CVD services at your organization coordinated with other services or care?
 - Services are coordinated **within organization** (i.e. coordination of client's care between departments within your clinic)
 - Services are coordinated **with other agencies/providers** (i.e. coordination of client's care between your site and referral sites)
 - Services are not coordinated
 - Don't know
4. Please check all the factors that influenced the design and implementation of your CVD related programs or activities.
 - Literature
 - National programs, activities or models
 - Local programs, activities or models
 - Guidance from funding source(s) or a legislative mandate
 - Input from advisory group(s)
 - Input from clinic staff
 - Input from clients and community members
 - Don't know
 - Other (specify) _____
5. What factors do you think contribute to the success of your CVD related programs or activities? For example has a group exercise program helped participants to stay on track towards their goals?
6. What successes have you seen from the CVD related programs or activities? For example, has participation increased or are participants losing weight/meeting goals?

APPENDIX B:

INTERVIEW QUESTIONS

Section 1: Background

1. Can you tell me a little about the history of [name of program]?
 - a. When did you first start offering this program?
 - b. Where did the idea for [program] come from?
 - c. How did you decide to focus on [smoking cessation/nutrition/physical activity/etc]?
 - d. Why was this approach taken?
 - e. Where did funding come from?
 - f. Do you partner with any other agencies or organizations on this program?
2. Can you tell me more about [program] itself?
 - a. Who is the target population?
 - b. Are there written goals or objectives? If so, what are they?
 - c. What activities are a part of the program? (For staff and for clients)
 - d. Why did you choose these activities?
 - e. What elements of program make it a good fit for urban AI/AN?

Section 2: Monitoring and Evaluation

3. What do you consider to be the key indicators of success for this program?
4. How do you track what the program is accomplishing?
5. What outcomes do you measure through this program?
6. How does staff collect and record outcomes information (checklists/forms/other instruments)?
 - i. How often is this information collected?
7. Are there any mechanisms in place for participants to provide feedback? If so, what are they?
 - i. How often is this information collected?

Section 3: Lessons Learned

8. Can you tell me about the greatest challenges you faced in implementing [program]?
 - i. What have you done to overcome these challenges?
9. What barriers have you encountered in maintaining [program]?
 - i. What have you done to overcome these barriers?
10. What changes have you made to [program] since it was first implemented to make it work better for staff? What about for clients?
11. What are key recommendations you would make for other UIHO that would like to implement a similar program?
12. What are specific considerations UIHO should take into account when deciding if this is a good approach for them?
13. Are there any resources you would recommend to UIHO interested in implementing a similar program?

Section 4: Closing

14. Is there any else you would like to share about [program]?
15. Could we list [program name]'s contact information for questions? If "yes": What is the best information to list?
16. Do you have any written materials, brochures or publications about this project you can share with me?

UIHI Publication Feedback Form

We are very interested in your feedback regarding this and other UIHI publications.

Please take a moment to detach and fill out the following form with your comments, questions and suggestions. Mail to the Urban Indian Health Institute, Seattle Indian Health Board, PO Box 3364, Seattle WA 98114 or fax to 206-812-3044. You can also fill this form out on-line at www.uihi.org. Thank you very much for your time.

I am commenting on the following UIHI publication:

I received this publication in the following way:

- Discussions with Urban American Indian and Alaska Native Parents (2011)
- Looking to the Past to Improve the Future (2011)
- Aggregate Urban Diabetes Care and Outcomes Audit Report (2010)
- Reproductive Health of Urban AI/AN Women (2010)
- Visibility Through Data (2009)
- Health and Health-Influencing Behaviors among Urban AI/AN (2008)
- Other: _____

- Electronic version sent to me directly
- UIHI (over email)
- Hard copy sent to me directly from UIHI
- Downloaded it from the website
- Someone in my agency shared it with me
- Someone outside my agency shared it with me
- Other: _____

Please share your thoughts, questions or comments about the publication:

Overall, did you consider this publication helpful? Yes No

What would have made it more helpful? _____

Overall, did you consider this publication easy to understand and use? Yes No

What would have made it easier to understand and use? _____

How do you intend to use this publication and the information it contains? (Check all that apply)

- Grants
- Program Planning
- Presentations
- General Background
- Unknown
- Advocacy
- Other: _____

If you would like a staff person to respond to your questions or comments, please share your contact information: Do you prefer to be contacted by: Phone Email

Name: _____ Agency: _____

Phone: _____ Email: _____



