PROMOTING INDIGENOUS HEALTH

A Collaborative Evaluation with Urban Indian and Tribal-Serving Organizations



Urban Indian Initiative

The <u>Urban Indian Initiative</u>, launched in November 2022 and sunset in May 2025, assisted in building community capacity for long-term COVID-19 recovery and resilience to better position Washington's Urban Indian communities for future public health emergencies. Urban Indians are tribal people living off federally defined Tribal lands in urban areas. Over the last century, Native people moved to, or were forced to relocate to, urban areas because of government policy, lack of economic opportunities, and limited access to healthcare and other services. Today, 7 out of 10 American Indians and Alaska Natives (AI/AN) live in urban areas (source: <u>Seattle Indian Health Board</u>). According to the Seattle Indian Health Board, although Urban Indians represent the majority of AI/AN people throughout the country, they are often overlooked.

The Center for Community Relations and Equity (CRE) at the Washington State Department of Health (DOH) partnered with 6 organizations that serve Urban Indian and Tribal communities across the state. Using a braided funding approach, which combines different funding sources, partners led community-rooted efforts to improve infrastructure, strengthen capacity, and address health and social conditions amplified by the pandemic. The partner organizations and their project types include:

Capacity Building Projects

- <u>American Indian Community Center</u>: Provided wrap around services and care coordination support to Urban Indian individuals and families who have COVID-19.
- <u>American Indian Health Commission:</u> Designed trauma informed training opportunities through Seven Generation Strategies as a path to healing for AI/AN people.
- <u>Chief Seattle Club:</u> Developed and implemented dedicated communications and information technology infrastructure to improve agency-wide emergency preparedness to better respond to future pandemics.
- <u>The NATIVE Project</u>*: Created a public health communications infrastructure including a new electronic health record (EHR) system and patient portal for real-time messaging, promotions, and information distribution.
- <u>Northwest Washington Indian Health Board</u>: Developed Natural Helpers/Healers Workshops utilizing evidence-based knowledge on Coast Salish strengths and protective factors to improve conditions of social isolation, anxiety, and depression exacerbated by COVID-19.

Data Equity for Indigenous Health Project

<u>Seattle Indian Health Board</u> (SIHB): Leads the Data Equity for Indigenous Health (DEIH) Project, an ongoing collaborative pilot project to improve how COVID-19 health data is collected, shared, and reported for AI/AN populations. SIHB uses a mix of Indigenous knowledge and modern data tools to better understand the health needs and strengths of Urban Indian communities, both locally and nationwide.

*The NATIVE Project was not able to participate in the evaluation due to their contract period of performance.

Evaluation Objectives

Between April 2023 and December 2024, CRE partnered with the <u>Center for Anti-Racism and Community Health (ARCH)</u>, University of Washington, to evaluate Urban Indian Initiative partnerships, with the following objectives:

- Describe how program-specific activities impact community resilience.
- Describe how we consider and operate equity in activities related to COVID-19 pandemic response and recovery.
- Describe the implementation and **impact** of activities to support community outreach, engagement, and equity in public health.

Evaluation Methodology:

- From March through September 2024, ARCH identified and interviewed 14 individuals from the *capacity* building projects and the DEIH Project (refer to page 1 for the list of projects).
- All interviewees answered questions based on these evaluation priorities:
 - Understanding Scope of Work
 - Relationship Building
 - Data Sovereignty
- An analysis based in Indigenous Evaluation and Anti-Racism (IE&AR) principles was used to explain themes from the recommendations.

ARCH Approach to Evaluation:

Center for Anti-Racism and Community Health (ARCH) created the evaluation approach (Figure 1) by applying Indigenous evaluation and anti-racism principles to the CDC Evaluation Framework. Key principles include:

- Colonization consciousness: awareness that U.S. policies are rooted in imperialism and a desire for material gain.
- Race(ism) consciousness: awareness of racial grouping processes that promote assimilation and exclusion as tools of power and how they work in colorblind environments.
- Stories as theory: recognize and use stories as valid and legitimate sources of data.
- Structural determinism: recognize how macrolevel forces (e.g., structures, policies, norms) drive inequities across time and space.



Figure 1: ARCH Evaluation Approach

References:

Brayboy BMJ. Toward a Tribal Critical Race Theory in Education. The Urban Review. 2005;37(5):425-446.

Ford CL, Airhihenbuwa CO. The Public Health Critical Race Methodology: Praxis for Antiracism Research. Soc Sci Med. Oct 2010;71(8):1390-8.

The approach aligns with the Community Based Participatory Research (CBPR) Conceptual Model (Figure 2). The CBPR Conceptual Model includes:

- Context
 - o Community assessment and power mapping
- Partnership Processes
 - Partnership building
 - Evaluation and conceptualization
- Intervention and Research
 - Data collection and analysis
 - Interpretation
 - o Dissemination
- Outcomes
 - Capacity building and action
 - Change in partner-identified metrics

Figure 2: CBPR Conceptual Model



CBPR Conceptual Model. Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010, https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html.

Urban Indian Initiative Evaluation Summary

The following are key themes from 4 Urban Indian/Tribal serving organizations participating in the capacity building projects.

Community Needs and Barriers

- Access is the barrier.
 - There is a need for clear, flexible, and sustainable (e.g. past single grant life cycle) funding pathways.
 - Structural racism limits access to data (e.g. exclusion from reporting systems during COVID-19).

- Communities face limited access to privatized healthcare.
- Historical trauma is the root cause of barriers.
 - Chronic health needs (i.e. substance abuse, suicide rates, cancer, diabetes, mental health needs) are rooted in historical trauma.
 - The lack of trust in government comes from racist policies against Indigenous communities.
- **COVID-19 worsened needs**, led to social isolation and loneliness, and brought unexpected loss of life in communities.

"It's racism. It's the idea that we can't let the Tribes have access to this information because there's non-Tribal information in there. I'm like 'Okay, but you're okay with the local health jurisdictions having access to Tribal information. It's the same issue. That's racism.' Racism's been the hardest thing."

Community Resilience

- Community resilience is a **generational** concept. It is all encompassing, from elders to children.
 - Communities measure resilience by children's happiness, health, and safety.
 - Resilience includes acknowledging the strengths of ancestors (i.e. living elders and ancestral elders).
 - o **Generational knowledge** and **sharing stories** are vital to resilience.
- Cultural identity is an anchor to resilience.
 - Being a part of a community builds a sense of self-worth. It establishes family and interconnectedness.
 - Resilience is building capacity for healing in community.
 Resilience is spiritual strength.
- At the same time, disagreement was expressed about the term "resilience" and its application to Urban Indian and other marginalized communities.
 - Native communities are tired of having to be resilient and surviving things. They feel forced to endure.

Equity and Community Integration

- Tribal and urban intertribal communities naturally take care of each other and integrate community - "bringing Native people together to be around other Native people."
- Tribal and urban intertribal communities naturally embed equity in everything they do - "it's not something we are actively trying to incorporate into the work, it is the work."
- Indigenous communities are united by a collective struggle, whether under the umbrella of "equity" or not.

Selection Process and Funding

- Most organizations subcontracted with Native owned businesses who they had established partnerships with and who had subject matter expertise. Subcontractors did not need technical assistance because of established partnerships.
- Participating organizations had varying projects. The uniqueness and range of topics among the four organizations were a strength of this program.

"We don't want to use that term resilient because it implies that there's been things that have knocked people down in order for them to bounce back...that means I'm a survivor of many things... that I would choose not to have and I'm surviving all of that, not because I want to be resilient or I want to survive things but because that's just what we've dealt with"

"You don't do equity by saying, 'Hey, you, the most vulnerable, the vulnerable people, you compete against each other, and we'll let you know who wins.'...It's very colonizing."

"The more you all can do the negotiation [to] let us be as expansive as possible in our definition of adequately meeting the funding expectations and guidelines, the more likely we are to be able to do things that are actually based in our data sovereignty... things that we know work. [We] have to shape them around your funding in order to make them work. And probably, more often than not, it'll actually limit the effectiveness of the strategy."

Partnership with DOH

• Successes:

- Technical assistance was provided for marketing materials and content creation.
- DOH had consistent check-ins and regular touchpoints and took on a more listening role.
- o DOH connected other organizations to support on projects.
- An AI/AN person serving as the program manager was extremely helpful in understanding terminology and background.
- The development and use of a standardized reporting tool reduced reporting burden.

Challenges:

- There was a lack of access to data.
- o There were inconsistencies with DOH approvals.
- o DOH communication was sometimes slow and prevented organizations' abilities to respond to their clients.
- Funding limitations prevented the purchase of food.

Data Equity for Indigenous Health Project Evaluation Results

Results: The table below presents the perspectives of evaluation participants from SIHB involved in the DEIH Project. These perspectives, obtained from in-depth qualitative interviews, are organized into three themes – definitions of data sovereignty, institutional policies that are deemed supportive, and institutional policies that need modification. All quotes are provided anonymously due to the small number of participants.

Definitions of Data Sovereignty

- Participants reported that data sovereignty requires ownership and control of data collected by them or on their behalf.
- Data sovereignty includes how we collect and use data, how we request consent, who collects the data, and who has access.
- Infrastructure must protect data sovereignty.
 - Build capacity by hiring individuals with lived experience and/or experience working with American Indian/Alaska Native
 (AI/AN) communities. This includes data and support staff.
 - Hiring individuals is not enough, the Washington State Department of Health (DOH) must also adequately resource projects.
- Staff needs training for building relationships and working with Tribes.
 - Include the understanding of tribal health jurisdictions, Tribal sovereignty, government-to-government relationship, and treaty rights in learning objectives.
 - We can identify policy and practice changes by questioning how public health surveillance conflicts with tribal sovereignty.

"There needs to be better training to staff on working with Tribes. I think there's been attempts to create a training, but it's never really been fully implemented with employees."

"I think it's time for us to really take back our own data because data is powerful. It tells a story. We can start rewriting that narrative and use the data to come from a strengths-based approach."

"One of the things that has happened historically to our community is that our population's data has been used almost in a weaponized way...focusing on deficits rather than strengths and opportunities."

Institutional Policies - Supportive

- DOH hired a Senior Tribal Epidemiologist who advocates for data sovereignty efforts.
- DOH hired a Native program manager for the DEIH Initiative.
 - This position advocates for Urban Indian/Tribal-Serving Organizations and data sovereignty issues.
- DOH ensured that tribes approved Data Sharing Agreements (DSAs).
- DOH included consultation with tribes in DSA creation.
 - DOH asked permission from each tribal Institutional Review Board (IRB). DOH also gave each tribal IRB time to review, despite short timelines due to grant requirements.
- DOH and partners promoted effective relationship building with in-person meetings and regular communications.
- Multiple participants noted that they believed DOH did not have supportive institutional policies about data sovereignty.

"DOH is a Western institution that really lacks internal policies supporting Indigenous data sovereignty, it's been really clear at this project, and it's just been such a huge barrier."

"I do think it's good that they [hired] a senior tribal epidemiologist...when we meet with various DOH data stewards who are hesitant about sharing their data, [they've] been a really strong advocate for Indigenous data sovereignty."

Institutional Policies - New or Modification Needed

- Streamlined and institutionalized process for DSAs.
 - There are currently no clear or formalized steps for this process.
 - Documented procedures must also include ways for tribal IRBs to approve DSAs.
- More comprehensive data collection.
 - More data on AI/AN populations from Western WA.
 - Data collection needs to change from a deficit approach (i.e., adverse health outcomes or conditions) to cultural strengths and acknowledgement of rich Native histories.
 - Deficits-heavy data reinforces social marginalization and conflicts with Indigenous principles including sovereignty.
- Lack of Colonial Consciousness within DOH.
 - Data stewards need to learn about legacy settler colonialism and the role of data surveillance in maintaining harmful narratives against AI/AN communities.
- Frequent DOH staffing changes. Bureaucratic barriers create delays in finalizing contracts and notice of awards.

"Every data steward for every data set is going to ask the same set of questions... you get involved in circular discussions that are about each of the data sets. 'Why do they need that?'. So, in the absence of some sort of process or procedure, we get stuck in that spiral."

"I think one thing that would be really good is to have DOH create a training on Indigenous data sovereignty and require all data stewards and people that work with data to take that training, because that's been a big barrier we've been coming up against when we meet with these new project teams."

Recommendations for Institutions

- Hiring individuals in support of Indigenous data sovereignty is essential. However, we need to identify
 more policy and practice changes to continue and expand these efforts.
- Continue to hire individuals with decision-making powers that can move Indigenous data sovereignty efforts forward and advocate for staff who may not understand.
- Document Data Sharing Agreements (DSAs) in a step-by-step process. This ensures we can create and replicate DSAs for different data sets and projects with community organizations.
- Create all-staff training about working with tribes. Create a training for data stewards on the institutional responsibility to protect Indigenous data sovereignty.
- Join Urban Indian/Tribal-Serving Organizations to advocate for learning opportunities on relationship building and professional development for institutional employees.
- Conduct listening sessions with organizations before funding calls to co-create scopes of work and ensure grants fit into community-identified priorities.
- Set up consistent in-person meetings (e.g., quarterly) with partners, in addition to virtual meetings.

For more information about this evaluation and the Urban Indian Initiative, please contact:

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