Centering Native Perspectives and Wisdom: Reframing Non-Indigenous Research on American Indian Health

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“Indigenous Peoples tend to approach health as an equilibrium of spirituality, traditional medicine, biodiversity and the interconnectedness of all that exists. This leads to an understanding of humanity in a significantly different manner than non-Indigenous peoples.”


Health and survival—and the societal conditions that shape them—have garnered widespread attention in the wake of the global COVID-19 pandemic. Cross-national studies reveal that the United States experienced some of the largest drops in life expectancy in 2020–2021, accelerating a long-standing disadvantage in health and survival relative to other high-income countries (figure 1). Within the US, the 2021 life expectancy of American Indian and Alaska Native people fell to 67 years, the lowest of any racialized group in the nation. To grasp the true significance of this statistic, we need only examine the recurring oppressive systems and environments that ultimately undermine our overall well-being.


Poor conditions of life and death in the US are being driven by intersecting realities,\(^4\) including rising economic inequality and precarity, social violence and exclusion, environmental pollution and degradation, as well as political polarization and instability. These societal conditions are a backdrop to other major ongoing public health epidemics and emergencies, including ones relating to obesity, addiction, violence, mass incarceration, and poor mental health. Although they affect everyone, these conditions are not borne equally across different groups of people and places.

For Indigenous Americans especially, whose presence on the continent long predates the establishment of the United States, the injustices inflicted over generations of colonization have resulted in cumulative harm. American Indian and Alaska Native communities experience some of the starkest health inequities,\(^5\) resulting in the worst population health outcomes of any racial or ethnic group in the country. These outcomes must be understood in light of the ongoing settler colonial conditions that gave rise to them, including profound historical injustices, many of which redound and


continue to this day. These harms, as summarized in a 2023 report of the United Nations Permanent Forum on Indigenous Issues, include the following:

- forced and often violent removal from homelands and/or the placing of Indigenous peoples on lands that are isolated, infertile, to be monitored and controlled
- separating Indigenous children from their families to be indoctrinated into the colonizer’s way of thought and religious practice through institutionally run schools that facilitate widespread abuse of children, also stealing children for adoption or slavery
- persecuting, incarcerating, and even murdering community members who make use of Indigenous practices, defend their lands, and protect Indigenous lifeways
- appropriating, commodifying, and capitalizing on Indigenous spiritual practices or traditional knowledge as discoveries, exploiting Indigenous practices and knowledge without proper education or permission
- invading and destroying sacred sites, disrupting ancestors’ remains, and mining for natural resources without permission
- using violence against Indigenous peoples who resisted the injustices and systems of colonization
- limiting Indigenous freedoms, autonomy, and self-determination through widespread incarceration in justice, health, and social service systems
- continuous racism, marginalization, exclusion, and negligence towards Indigenous peoples enacted systemically and structurally in denial of fundamental rights and freedoms

The purpose of this review is not to document the current state of American Indian health, which has been done by both Native and non-Native scholars and organizations. The latter often lack critical context relating to important limitations in the data, structural drivers of Indigenous health and health protective factors, or Indigeneity itself as an overarching determinant of health. They also ignore the sovereignty of Native Nations over the health of their people and their environments and Indigenous data sovereignty. Instead, we aim to widen the lens—for non-Native researchers and others—on the many factors and conditions that matter to the health, well-being, and flourishing of American Indians.

The following sections provide a high-level overview of some of the key policies and practices affecting the health and survival of American Indians historically and today. We then review how Native conceptions of health and well-being deviate from dominant Western paradigms and how Native and

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8 Indigenous Determinants of Health in the 2030 Agenda for Sustainable Development, United Nations, p.3.
other Indigenous approaches encompass much broader, deeper, and holistic worldviews of what constitutes health and a healthy society. We conclude with a brief discussion on decolonizing research, Indigenous knowledgemaking, and data sovereignty. Each of these topics is touched upon only lightly. These and related topics are always best explored through the streams of knowledge, guidance, and experiences of Native people.

Song about the departure of Seminole Indians from Florida for Oklahoma (vocals) performed by Katie Smith and Courtney Parker at Brighton Indian Day School, Cow Creek settlement, Seminole Indian Reservation, Florida, on July 1, 1940: https://www.loc.gov/item/flwpa000357/.

Brief History of US Policies and Practices Affecting Native Communities

“What we know, particularly for indigenous people, is that there was a genocide and assimilation policies and termination policies that were perpetuated against us. If they had worked, we wouldn't be here. And so, we were always strength-based people, who passed on and continued knowledge systems regardless of people who tried to destroy us.”

—Abigail Echo-Hawk

Read the full interview here: https://crosscut.com/2019/05/abigail-echo-hawk-art-and-science-decolonizing-data

The history of Native peoples and the US is marked by a legacy of colonial oppression, racism, and systemic injustices that have profoundly impacted the health of Native communities. To lay the policy context and complexities of Native health, the following sections will explore major historical events that have shaped the health disparities of Native communities. While not exhaustive, these key points will provide insights into how structural disparities in Native health have unfolded in the US.

Colonization, Land Theft, and the Reservation System

Colonization, marked by the arrival of European settlers in ancestral Native lands, disrupted the traditional practices and ecological balance established by Native peoples. Driven by the relentless expansion of European settlement, this period brought forth new and deadly diseases, starvation, calls for genocide, and land theft. Native peoples were also subjected to a system of bondage that is poorly understood and often hidden. Between the arrival of Christopher Columbus and the 20th century, it is

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estimated that 2.5 to 5 million Native People were enslaved,\textsuperscript{12} often targeting women and children for domestic labor and forced reproduction.

Forced removals from ancestral lands were a result of colonizers stealing lands in the name of American progress with government-backed assistance. As tribes resisted assimilating to European culture, policies and practices were crafted to make land easier to claim from Native peoples, including pressuring and bribing Tribal nations into signing land agreements under false pretenses.\textsuperscript{13} In 1830, The Indian Removal Act authorized the federal government to grant Native lands to settlers eager to raise cotton and mine for gold. As a result, the US government forcibly removed tribes from their ancestral homelands by federal troops and relocated an estimated 100,000 Native people into unfamiliar, isolated, and considered worthless lands.\textsuperscript{14} Native families were separated, the elderly and ill were forced out at gunpoint, and white looters loomed behind, ransacking Native communities as they were led away or held in internment camps.\textsuperscript{15}

A prominent example of this brutal and deeply traumatic event is known as the Trail of Tears, which is specific to the removal of the Cherokee, Choctaw, Chickasaw, Creek, and Seminole tribes into modern-day Oklahoma. As groups traveled hundreds of miles west by foot, they faced disease, famine, and injury,\textsuperscript{16} which was especially hard on infants, children, and the elderly. Many died, though official accounts are not available. These traumatic events are interwoven and remembered in Native culture, an example of which can be heard in a 1940 recording of a sung story about the Seminole tribe’s removal from Florida and travel to Oklahoma.\textsuperscript{17}

The Indian Appropriations Act of 1851 established Indian areas, which were small, geographically isolated areas, also known as reservations. Violent conflicts between the US government and tribes were common, with the Lakota genocide at Wounded Knee exemplifying the violent response of the US government to Native resistance to genocide. With restrictions on Native peoples’ ability to hunt, fish, and gather food in their traditional ways coupled with unmet government promises to support relocated tribes, illness, starvation, and depression ensued.\textsuperscript{18}

The Dawes Act of 1887, also known as the General Allotment Act, was a pivotal piece of legislation in the United States aimed at assimilating Native communities by breaking up communal land

\textsuperscript{15} “What Happened on the Trail of Tears?,” National Park Service.
\textsuperscript{16} “What Happened on the Trail of Tears?,” National Park Service.
ownership and allotting individual parcels to Native families while selling the remaining land to non-Natives. While proponents of the Dawes Act argued this would encourage Native communities to adopt a more agrarian and individualistic lifestyle, the consequences were detrimental to their health. The division of tribal lands often resulted in furthering the loss of traditional hunting and gathering grounds, disrupting established patterns of sustenance. Additionally, the forced assimilation efforts, including the imposition of Euro-American agricultural practices, led to nutritional deficiencies and an increased vulnerability to diseases among Native populations. By the time the Dawes Act and its subsequent amendments were fully implemented, Native communities lost approximately 90 million acres of collectively held land. This loss had profound and lasting effects on Native cultures, economies, and ways of life, contributing to the erosion of traditional practices and the impoverishment of many Native communities.

In the US today, there exist 574 federally recognized Tribes and 326 reservations spanning over 56.2 million acres of land trusts largely marked by deficient infrastructure, disinvestment, and resource extraction. Reservation lands subsequently marginalized Tribes from pivotal sectors of historical and contemporary US economies. Concurrently, this displacement has rendered Native communities vulnerable to amplified risks and perils associated with climate change, prominently manifesting as intensified heat waves, wildfires, hurricanes, and the dwindling availability of traditional and modern water sources. This stark reality is underpinned by recent research revealing that Tribes have suffered a staggering 99 percent loss of their ancestral lands, underscoring the immense magnitude of this land loss. This is the genesis of the Land Back movement, which lies in the endeavor to deconstruct this structural symptom of white supremacy, advocating for the restoration of Indigenous lands to Indigenous hands.

**Residential Boarding Schools**

After relocating and restricting Tribes, the US government began to institutionalize acts of cultural genocide through the veil of religion and education. The first government- and church-operated Indian boarding schools began in the mid-to-late nineteenth century to assimilate and acculturate Native children into mainstream American culture. Initially forcing Native families to send their children away, and then later being the only viable schools available to Native children, these schools aimed to extinguish every aspect of Native culture and life, as reflected in the phrase “kill the Indian, and save the man.” Children were separated from their families for long periods, given English names, forced to cut their hair, trade their clothing for uniforms, punished for speaking their own languages, and forced to replace traditional cultural practices with Christian ones. Curriculums taught children that their cultures were inferior, teaching students to be ashamed and ridiculing ancestorial teachings and beliefs.

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19 Bureau of Indian Affairs, “Indian Entities Recognized by and Eligible To Receive Services From the United States Bureau of Indian Affairs,” Federal Register 88, No. 8 (2023).


Imitating military organizations, rules at these schools were very strict and discipline harsh, including corporal punishment, forced labor, as well as sexual and mental abuse. Tens of thousands of Native children attended these 408 boarding schools, peaking in the 1970s with an estimated enrollment of 60,000 in 1973.

These schools had notoriously poor living conditions with overcrowded and poorly constructed dormitories, inadequate nutrition, and insufficient sanitation that helped spread deadly communicable diseases such as tuberculosis and trachoma. In addition to the physical health ailments, many were reported to be in poor mental health, with reports of 23 percent of high school students attending Indian boarding schools attempting suicide and 33 percent reporting suicidal ideation. Tragically, these schools were also places where Native children went to die. In 2021, the US Secretary of the Interior and the first Native woman to hold the position, Deb Haaland, launched the Federal Indian Boarding School Initiative. The initiative’s 2022 investigative report uncovered at least 53 burial sites for children across these schools, with the expectation of more to come. A preliminary analysis revealed that over 500 Indigenous children died in approximately 19 of these schools, underscoring the toll of the Federal Indian boarding school system. Further, these boarding schools nearly achieved what they intended: by intentionally separating children from their communities, generations of parents and elders were prevented from passing their knowledge, language, and culture through story-telling and other oral traditions to the next generation.

28 “American Indian Boarding Schools,” Georgia State University Library.
Termination and the Urban Indian Relocation Program

As the US government continued its assimilation policies, Congress passed the Termination Policy of 1953, which aimed to dismantle tribal communities, dispose of their land rights, and relocate Native peoples from reservation lands to urban areas under the guise of a shot at economic mobility. This terminated Tribes’ recognized relationships with the federal government, access to government services, and resources meant to serve Native communities.

This policy had severe negative consequences for public health and equity, accelerating cycles of injustice for Native communities by further disrupting social structures, traditional practices, and access to essential resources. Upon relocation, many Native individuals had little access to job opportunities,
quality education, or adequate social services, all weighted by racist systems that aimed to exclude and oppress them. These disparities contributed to poorer health outcomes and hindered the overall well-being of the community and its members. The urban environment, unfamiliar to many, often lacked the cultural support, community, and resources necessary for maintaining health. Within five years, approximately 50 percent of those who moved to urban areas chose to return to their families and reservations. Today, the effects of these policies, coupled with economic hardships and lack of educational opportunities, have translated to over 71 percent of Native peoples living in urban areas, off-reservation lands. To many researchers and health advocates in the US, this urban population is invisible, leaving the experiences, health, and needs of 7 in 10 Native peoples unconsidered, underfunded, and unaddressed.

Unmet Promises of Health, Housing, and Education

As Native lands and resources were ceded to white settlers, the federal government entered into numerous treaties—367 between 1778 and 1868 alone—to guarantee "proper care and protection" for Native peoples’ access to health, housing, and education. Upheld by the Constitution’s supremacy clause, these treaties established trusts with the federal government, charging it with the highest responsibility to fulfill its obligations. However, despite leveraging lands and resources, the government has yet to fully actualize its end of the deal.

From the outset of these treaties to today, the problem of insufficient funding for these promises has been evident. A stark example of this disparity can be seen as early as the 1890 Annual Report of the Commissioner of Indian Affairs, which revealed that government physicians working with Native peoples were significantly underpaid, earning an average annual salary of $1,028 compared with the $2,823 earned by Army physicians. Unfortunately, this trend of limited funding continued to affect vital services such as the Indian Health Services (IHS) and its predecessors, leading to aging infrastructure and inadequate personnel. This chronic underfunding can be attributed in part to the historically unmet pledges by the federal government and a series of policies that have shaped this unequal ecosystem. Next, we discuss policies aimed at creating supportive systems to meet the needs of Native communities.

The Snyder Act of 1921 was the first law that allowed Congress to allocate funds for Native peoples’ health regularly. It empowered the Bureau of Indian Affairs (BIA) under the Department of the Interior to direct and supervise these funds for the benefit and care of Native peoples throughout the US. This paternalistic funding authority laid the groundwork for the IHS’s current activities. In the

34 Warne and Bane Frizzell, “American Indian Health Policy: Historical Trends and Contemporary Issues.”
Transfer Act of 1954, the Indian health program became the responsibility of the Public Health Service, which recognized tribal sovereignty and self-determination by allowing the Surgeon General to administer health facilities for Native peoples and enter into contracts with Tribes for the transfer of hospitals or health facilities, subject to tribal approval.

The Indian Self-Determination and Education Assistance Act (ISDEAA) of 1975 marked a major power shift, allowing Tribes to manage BIA and IHS programs through self-determination contracts. Tribes can operate health programs as federal contractors or via block grants. ISDEAA benefits Tribes with carry-over funding, grant eligibility, third-party revenue collection, and contract support costs, opening previously unavailable funding opportunities to Tribes. Over time, more than half of the IHS budget has been managed by Tribes under ISDEAA, but many tribal leaders say this funding is inadequate, citing continually underfunded services.

The Indian Health Care Improvement Act (IHCIA) of 1976 expanded and described modern health services, establishing Urban Indian Health Programs and allowing IHS and tribal health programs to bill Medicare and Medicaid, facilitating expanded access to services. With the passage of the Affordable Care Act in 2010, IHCIA was permanently reauthorized.

Overall, this legislative history has significantly shaped the health care delivery system for Native peoples, represented by the "I/T/U" system, with IHS, 638 tribal health programs, and Urban Indian Health Programs providing health care services. While these laws have sought to advance the well-being of Native peoples, challenges remain, particularly with underfunded services and social determinants of Native health that continue to undermine the health and well-being of Native communities.

Native communities continue to resist these structural systems of oppression that deeply impact Native health, but these pervasive effects bleed into every aspect of Native communities’ every stage of life from birth to death. These long-standing and superficial solutions continue to impede the overall well-being of Native populations, resulting in unbroken harmful systems and intergenerational trauma, furthering health disparities. However, there lies hope in empowering Native communities to embark on healing, fostering ecological health, and reclaiming and revitalizing their cultural heritage, much of which reflects deeply held wisdom with answers to our modern-day threats such as climate change, public health, agriculture, technology, and more. In the following section, we will delve into these transformative efforts that hold the potential to bring about positive change and resilience within Native communities.

35 Warne and Bane Frizzell, “American Indian Health Policy: Historical Trends and Contemporary Issues.”
36 Warne and Bane Frizzell, “American Indian Health Policy: Historical Trends and Contemporary Issues.”
37 Warne and Bane Frizzell, “American Indian Health Policy: Historical Trends and Contemporary Issues.”
Native Models of Health and Well-Being

Native peoples consist of a large and diverse group of people, and there is no single American Indian culture, language, or perspective. In the US, the federal government decides which Native Nations are “recognized” and which individuals can claim Native identity under federal law. Currently, there are 574 federally recognized Native Nations (i.e., Tribes, Nations, Bands, Pueblos, communities, and Native villages) and about 63 state-recognized Tribes (although the latter does not confer any benefits under federal law). The unique political relationship Tribes have with the US federal government is important to understand. As explained by Native scholar Kimberly R. Huyser:

Federally recognized tribes are subject to the U.S. federal government’s trust doctrine—a legal and moral duty to assist in the protection of tribal lands, resources, and cultural heritage—and plenary power, which broadly maintains the federal to tribal governmental relationship. This relationship was generated from the treaties between the U.S. government and tribal nations. In these treaties, tribes exchanged vast amounts of land to the U.S. to protect themselves from attacks upon their lands, for the U.S. to provide health care, education, to acknowledge and protect sovereignty and religious freedom, and to confirm and protect certain rights of self-government, fishing and hunting rights, and jurisdiction over their own lands.

Although individual American Indians can have one or more Tribal affiliations (a self-identified ethnic identity), not all are enrolled as citizens of a sovereign Tribal nation (a political identity), and not all live in states in which federally recognized Tribes have an organized presence or tribal government to represent their interests. According to the 2020 US Decennial Census, which systematically undercounts people living on Native lands, 87 percent of people who identify as American Indian/Alaska Native alone or in combination live outside of tribal statistical areas, and the remaining 13 percent live on reservations or other trust lands.

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42 Huyser, “Data & Native American Identity.”

“For Indigenous Peoples of the Americas, the creation of borders that have been imposed upon tribal nations has led to a tremendous loss of land, natural resources, culture, food systems, language, economies, and a thousand generations of traditional knowledge.”

—Donald Warne

Read the full article here:

https://ssir.org/articles/entry/walking_through_truth_indigenous_wisdom_and_community_health_equity

Building on long traditions of independence and activism, Indigenous scholars, leaders, and knowledge keepers in the US and globally have recently come together to advance and “attempt to explain in Western terminology” alternative Indigenous-centered understandings of collective health and well-being. Many of these efforts compare and contrast their insights with prevailing frameworks and systems that dominate “advanced” Western countries and institutions.

Two prominent examples, one by a group of US-based Indigenous scholars and one by an international group of Indigenous leaders, are presented in tables 1 and 2, respectively. As table 1 powerfully illustrates, there are many dimensions on which Indigenous and Western worldviews differ. They include how health and well-being are understood, by whom, and most importantly, what (if any) linkages and interconnections are made (1) between various aspects of an individual’s health, namely physical, mental, social, and spiritual; (2) between a single person and groups of people, including families, communities, and even ancestors and future generations; and (3) between people and other forms of life and life-sustaining aspects of the natural world, such as land, water, and air. These contrasting views of health and its determinants also reflect different ways of being (ontology) and knowing (epistemology).


### TABLE 1
Determinants of Health: Indigenous Knowledge and Western World Views

<table>
<thead>
<tr>
<th>Non-Indigenous knowledge base in the WHO social determinants of health framework</th>
<th>Indigenous knowledge of determinants, health, and well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Based on Western values of framework</td>
<td>Connects with community values, language, culture, land, place, stewardship</td>
</tr>
<tr>
<td>Voice of the “other”</td>
<td>Indigenous voice</td>
</tr>
<tr>
<td>Descriptive</td>
<td>Action-oriented</td>
</tr>
<tr>
<td>Prescriptive</td>
<td>Community determined</td>
</tr>
<tr>
<td>Linear</td>
<td>Holistic</td>
</tr>
<tr>
<td>Focuses on “closing the gaps” between subpopulations and the general or dominant population</td>
<td>Aligns movement with the community’s own vision of a healthy, sustainable society</td>
</tr>
<tr>
<td>Broadly applicable to all communities</td>
<td>Flexible for application in many communities</td>
</tr>
<tr>
<td>Decontextualized in time and spiritual space</td>
<td>Incorporates history and spiritual place</td>
</tr>
<tr>
<td>Lacks relational considerations among people and between people and the nonhuman world</td>
<td>Considers future generations and ancestors, intergenerational, including a role for each community member</td>
</tr>
<tr>
<td>Distinctions made between social, individual, biological and genetic, physical, and other determinants</td>
<td>Interconnectedness of all determinants</td>
</tr>
<tr>
<td>Focused on the individual</td>
<td>Focused on the collective and the individual's role in the collective</td>
</tr>
<tr>
<td>Determinant indicators and health outcomes primarily Western-defined disease prevalence and incidence rates, economics, education, and other measures</td>
<td>Metrics and measurements reflect Indigenous conceptions of health and society, including Indigenous community-specific economic activities, e.g., individual or small business art production and sales; tourism</td>
</tr>
<tr>
<td>Determinants indicators and health outcomes assume that communities have access to data to measure, assess, and track progress</td>
<td>Lack of data available at the nation, reservations, and tribal citizen levels; Indigenous data need to reflect Indigenous conceptions of health, well-being, and determinants</td>
</tr>
<tr>
<td>Deficit-based</td>
<td>Asset-based</td>
</tr>
<tr>
<td>Disease-based</td>
<td>Health-based</td>
</tr>
</tbody>
</table>


At the international level, Indigenous scholars, practitioners, land and water defenders, Elders, and knowledge keepers have also come together to identify Indigenous determinants of health and planetary health, which is intrinsically tied to the well-being of Indigenous people. Given that

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46 *Indigenous Determinants of Health in the 2030 Agenda for Sustainable Development*, United Nations, p.3; Nicole Redvers, Yuria Celidwen, Clinton Schultz, Ojistoh Horn, Cicilia Githaiga, Melissa Vera, Marlikka Perdrisat, et al.,
Indigenous people steward 80 percent of the world’s remaining biodiversity, their well-being is also intimately tied to humanity and other forms of life.

In what has been described as “the first global Indigenous-led organizational effort to specifically increase visibility and awareness of the health and well-being of Indigenous people” from an Indigenous worldview,\textsuperscript{47} a 2023 report adopted by the United Nations Permanent Forum on Indigenous Issues identifies Indigeneity as an overarching determinant of health:

**Indigeneity as an intersectional determinant of health across sectors.** Being Indigenous must be considered an overarching determinant of health for all social aspects because: (a) Indigenous Peoples’ interactions and connections to social life and environmental elements are substantially distinct from those of all other populations around the globe; and (b) the effects of the imposed systems, either by past colonial powers or current Governments, have negatively impacted, targeted and attempted to obliterate Indigenous systems across multiple generations. This has created a compounded negative effect that permeates and interlinks across all cultural, political, socioeconomic and biopsychological circumstances for Indigenous Peoples and communities.\textsuperscript{48}

An additional 33 interrelated Indigenous determinants of health (along with 37 important recommendations) are identified, described, and organized into three broad clusters: intergenerational holistic healing, health of Mother Earth, and decolonizing and re-Indigenizing culture. The report also maps these 33 Indigenous determinants of health onto WHO’s 13 social determinants of health levers. The first four, shared as examples, are as follows (italicized ones are health risk factors, and nonitalicized ones are health protective factors):

\begin{itemize}
\item Indigenous Determinants of Health in the 2030 Agenda for Sustainable Development, United Nations, p.3.
\end{itemize}
## Table 2

### Indigenous Determinants of Health Linked to Four of WHO’s 13 Social Determinants of Health Levers

<table>
<thead>
<tr>
<th>Health sector</th>
<th>Food systems</th>
<th>Economic systems</th>
<th>Racism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intergenerational approach</td>
<td>Indigenous food systems</td>
<td>Physical: environment ecology, limited access to Indigenous food systems resources</td>
<td>Institutionalized Indigenous-specific racism</td>
</tr>
<tr>
<td>Holistic healing</td>
<td>Mass-produced ultra-processed foods replacing Indigenous diets</td>
<td>Misconstruction of food security for Indigenous peoples and communities</td>
<td>Justified institutional pathologizing of Indigenous peoples</td>
</tr>
<tr>
<td>Indigenous culture and language</td>
<td>Access to and health of traditional plants</td>
<td>Environmental dispossession</td>
<td>Indigenous-specific targeting stigma</td>
</tr>
<tr>
<td>Sacred practices</td>
<td>Indigenous traditional medicine</td>
<td>Access to water sources</td>
<td>Ongoing trauma exposure</td>
</tr>
<tr>
<td>Indigenous spirituality</td>
<td></td>
<td>Structured, systematic and planned invisibility</td>
<td>Forced assimilation and indoctrination</td>
</tr>
<tr>
<td>Over-reliance on Western approaches</td>
<td></td>
<td></td>
<td>Dismissal of traditional medicine approaches</td>
</tr>
<tr>
<td>Suppression and oppression by substances</td>
<td>Indigenous traditional medicine</td>
<td></td>
<td>Structured, systematic and planned invisibility</td>
</tr>
<tr>
<td>Indigenous traditional medicine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structured, systematic, and planned invisibility</td>
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</tbody>
</table>

These two recent efforts to widen the lens and reframe Native health for others to understand and build on much deeper traditions and understandings of health and well-being within Native communities. One important model in North and South America is the Medicine Wheel, which has been used in various ways to represent multiple aspects of individual, family, community, and ecological health.

Also called the Sun Dance Circle or Sacred Hoop, the Medicine Wheel is an ancient and sacred symbol: a circle divided into four equal parts, with each quadrant representing vast teachings. Each direction of the wheel represents different aspects or stages of human development, experience, connection, and ways of knowing, and all quadrants are equally important for a balanced and healthy existence, individually and collectively. Although different groups attribute different gifts and meanings to the four positions on the wheel, one general overview describes them as follows (table 3):
### TABLE 3
Lessons and Gifts from the Four Quadrants of the Medicine Wheel

<table>
<thead>
<tr>
<th>Lessons and gifts from the EAST, the place of first light, spring, and birth, include:</th>
<th>Lessons and gifts from the SOUTH, the place of summer and youth, include:</th>
<th>Lessons and gifts from the WEST, the place of autumn and adulthood, include:</th>
<th>Lessons and gifts from the NORTH, the place of winter and elders, include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>◼ Warmth of the spirit</td>
<td>◼ Generosity, sensitivity, and loyalty</td>
<td>◼ Dreams, prayers, and meditation</td>
<td>◼ Intellectual wisdom</td>
</tr>
<tr>
<td>◼ Purity, trust, and hope</td>
<td>◼ Romantic love</td>
<td>◼ Perseverance when challenged</td>
<td>◼ Ability to complete tasks that began as a vision</td>
</tr>
<tr>
<td>◼ Unconditional love</td>
<td>◼ Testing of the physical body/self-control</td>
<td>◼ Balance between passionate loyalty and spiritual insight</td>
<td>◼ Detachment from hate, jealousy, desire, anger, and fear</td>
</tr>
<tr>
<td>◼ Courage</td>
<td>◼ Gifts of music and art</td>
<td>◼ Use of personal objects, sacred objects</td>
<td>◼ Ability to see the past, present, and future as interrelated</td>
</tr>
<tr>
<td>◼ Truthfulness</td>
<td>◼ Capacity to express feelings openly in ways respectful to others</td>
<td>◼ Understanding of life's meaning</td>
<td></td>
</tr>
<tr>
<td>◼ Guidance and leadership</td>
<td></td>
<td>◼ Fasting, ceremony, self-knowledge, and vision</td>
<td></td>
</tr>
<tr>
<td>◼ Capacity to remain in the present moment</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


The Medicine Wheel has also been used in various ways to support research: 49 as a conceptual framework, an evaluation framework, and a methodological framework to guide the development of appropriate measures, collect data, and then analyze and interpret the findings. Figure 2 shows a visual representation of the Medicine Wheel 50 to blend Native and non-Native approaches to study the treatment of intergenerational trauma and substance use disorders.


Another continuously evolving Indigenous-focused model that has been gaining traction in the Native research field is the Etuaptmumk (translated gift of multiple perspectives) or Two-Eyed Seeing model. An approach that honors Indigenous knowledge as equal to that of Western knowledge, Two-Eyed Seeing centers on principles of community-led engagements and the importance of co-learning to
better understand and address the topic of interest. The goal of this learning process model is to bring together the strengths of both Indigenous and Western knowledge for the benefit of all. In a meta-analysis of the use of this model, the major descriptive categories included a guide for life, responsibility for the greater good and future generations, a co-learning journey, multiple or diverse perspectives, spirit, decolonization and self-determination, and humans being part of ecosystems.

“Two-Eyed Seeing is hard to convey to academics as it does not fit into any particular subject area or discipline. Rather, it is about life: what you do, what kind of responsibilities you have, how you should live while on Earth... i.e., a guiding principle that covers all aspects of our lives: social, economic, environmental, etc.”
—Elder Albert Marshall, Mi’kmaw

Read the full article here: https://link.springer.com/article/10.1007/s13412-012-0086-8

As expressed by the opening quote, many American Indians, like other Indigenous communities around the world, have a fundamentally different understanding and approach to the world and what makes for a healthy and sustainable society. These worldviews sharply contrast the prevailing systems that govern life conditions in the US and most other Western countries. This contrast was also evident to Black Elk, a Lakota traditional healer who lived in the late 1800s and early 1900s and who traveled to Europe as part of Buffalo Bill’s Wild West show:

I could see that the Wasichus [Europeans] did not care for each other the way our people did before the nation’s hoop was broken. They would take everything from each other if they could, and so there were some who had more of everything than they could use, while crowds of people had nothing at all and maybe were starving. They had forgotten that the earth was their mother.


Indigenous Data Sovereignty

As sovereign nations, Tribal nations have the inherent right to govern every aspect of the collection, ownership, and use of data relating to their people, lands, and inherited knowledge systems. Indigenous data sovereignty is realized through the joint practice of Indigenous data governance and decolonizing data. A longstanding and growing worldwide data sovereignty movement among Indigenous communities and their leaders is working on multiple fronts and levels of government to reclaim data—and the research and evaluation enterprise surrounding data—pertaining to their communities, lands, and cultures.

Most Western approaches to Native data and research have continuously failed to provide accurate and fair representation: they have created and perpetuated paternalistic deficit-centered pathologizing narratives, frames, and stereotypes and undercounted, misidentified, and mischaracterized almost every aspect of Native life and culture. In responding to WHO’s framework on the social determinants of health, for example, Native scholars have noted how the framework reflects “an active voice of the other—the dominant, white, settler population—as those working, helping, and saving to reach health equity for a subpopulation, e.g., Indigenous peoples, instead of leading with communities’ knowledge and episteme.”

Fortunately, the movement toward Indigenous data sovereignty is independent of anything Western researchers may or may not do (although there is much we can do). As many Native scholars and leaders have attested:

Data are not a foreign concept in the Indigenous world. Indigenous peoples “have always been data creators, data users, and data stewards. Data were and are embedded in Indigenous instructional practices and cultural principles.” For example, many Indigenous knowledge systems were based on generations of data gathering through observation and experience that then informed Indigenous practices, protocols, and ways of interacting with other people and with the natural world. The translation of knowledge into data was similarly evident. Indigenous data were recorded in oral histories, stories, winter counts, calendar sticks, totem poles, and other instruments that stored information for the benefit of the entire community.

Indigenous data systems center on interdependence, not the acquisition of individual knowledge. While the acquisition and transmission of knowledge by individuals is necessary to support the collective base, Indigenous data systems rely on shared responsibilities to ensure that Indigenous ways of knowing, being, and doing are transmitted from one generation to the next. Within this context, knowledge belongs to the collective and is fundamental to who Indigenous nations are as peoples. Similarly, data that inform Indigenous ways of knowing are also

collectively held. While individuals hold knowledge (stories, songs, knowledge of special relationships with the natural world), they have roles and responsibilities to the collective to steward this knowledge.\textsuperscript{57}

Indigenous data sovereignty requires the joint practice of Indigenous data governance (collective oversight over every aspect of conception, collection, analysis, and use of data) and decolonizing data. Decolonizing data is the subject of a large and evolving body of knowledge and practice. Among the strategies that have been proposed to reclaim and decolonize tribal data and data systems are “rebuilding community trust in research, improving data accuracy and quality, promoting Indigenous methodologies and epistemologies, developing local capability, supporting self-determination, and producing meaningful and relevant data for decisionmaking.”\textsuperscript{58} Another important component of Indigenous data sovereignty efforts is calls for aligning external (non-Tribal) data systems to meet tribal needs.\textsuperscript{59}

In addition to systematically documenting specific tribal, nontribal, urban, intertribal, and supratribal Indigenous data governance and decolonization strategies in the US,\textsuperscript{60} efforts are also advancing to develop principles of Indigenous data governance and other forms of directed guidance (e.g., for philanthropic sponsors of research). The Urban Indian Health Institute,\textsuperscript{61} for example, has identified the following principles for decolonizing data specific to American Indian and Alaska Native people:\textsuperscript{62}

- We have a legal right to data governance through treaty and trust responsibility.
- We are accountable to past, present, and future generations.
- We are restoring cultural and spiritual practices that include belief systems that are contrary to Western religious practices. This includes but is not limited to spiritual connections to land and animals that inform data practices, beliefs in ancestors guiding data, and other cultural practices that vary by tribe and region.
- We have a responsibility to sustain and build forward tribal strength and vitality.
- Tribal affiliation and/or tribal enrollment data collection is specific to criteria outlined by each unique tribal nation.

Their vision for the future of all Native data methodologies includes the following:

- acknowledgment of harmful data practices coupled with healing, restoration, and reparations
- strengths-based data collection, analysis, and dissemination
- protective community and cultural factors measured and weighted against disparities and gaps

\textsuperscript{57} Carroll, Rodriguez-Lonebear, and Martinez, "Indigenous Data Governance."
\textsuperscript{58} Carroll, Rodriguez-Lonebear, and Martinez, "Indigenous Data Governance," p.11.
\textsuperscript{59} Small-Rodriguez and Akee, "Identifying Disparities in Health Outcomes and Mortality."
\textsuperscript{60} Carroll, Rodriguez-Lonebear, and Martinez, "Indigenous Data Governance."
\textsuperscript{61} “Urban Indian Health Institute,” https://www.uihi.org/, accessed February 6, 2024.
\textsuperscript{62} J. Magee, S. Gurule, A. Echo-Hawk, Urban Indian Health Institute, and Seattle Indian Health Board, “Decolonizing Data,” (Seattle: Urban Indian Health Institute, 2023).
• community governance every step of the way (collection, analysis, dissemination)
• accurate data reporting of race and ethnicity
• embedded accountability of entities for collection of race and ethnicity
• disaggregation of data by race, ethnicity, and multiple races
• undoing STEM education disparities
• exploring and refining small populations methodologies
• acknowledging community knowledge and investing in data capacity as informed by the community

First Nations Development Institute\(^6\) has developed lists of specific actions (to do and stop doing) directed at philanthropic funders of research relating to Native communities and ways they can promote Indigenous data sovereignty within their organizations and the philanthropic sector more generally. As they explain:

In philanthropic and other kinds of grant-funded work, Native communities have not been the architects of program evaluations. They are typically not engaged in designing measures and rarely receive the outcomes of research or evaluation conducted on their communities. Native evaluators are also not used for evaluation or are engaged only as an afterthought. This has been and continues to be standard practice of evaluation by a variety of funding organizations and agencies.\(^4\)

Finally, also in development are a variety of frameworks and principles intended to guide and protect Indigenous data (including traditional knowledges) in the face of rapid advances in machine learning, open data, and big data initiatives. After a year-long consultative process, the Global Indigenous Data Alliance\(^5\) released in September 2019 the CARE Principles for Indigenous Data Governance, with the four components of CARE: Collective Benefit, Authority to Control, Responsibility, and Ethics. The CARE Principles (figure 4) are both people- and purpose-oriented and were developed to strengthen and complement the existing FAIR Guiding Principles for scientific data management and stewardship (the four data-centric components of FAIR being Findable, Accessible, Interoperable, and Reusable).

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Among the many inherent and preexisting rights of Tribal nations and Native communities are those governing data sovereignty. Indigenous data sovereignty—and all that it requires and implies—is also acknowledged in Article 31 of the United Nations Declaration on the Rights of Indigenous Peoples, which states the following:

1. Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.

2. In conjunction with Indigenous peoples, States shall take effective measures to recognize and protect the exercise of these rights.

Some Final Thoughts

As American Indian and other Indigenous communities around the world claim their full rights and sovereignty and reclaim their data, worldviews, and ways of knowing, researchers and others outside the Native community should be learning, reframing, and reenvisioning research relating to Native people and places. As this review has started to show, underpinning the single alarming estimate of the low life expectancy of American Indians today is an entire history, set of policies, and resulting life conditions that have been imposed on the original inhabitants of this land, all of which are often unacknowledged by non-Native researchers and others, if they are known at all.

Also underrecognized and undervalued—by mainstream Western scholars and others—are entire life-sustaining, health-promoting world views and lifeways that have sustained Indigenous communities and the planet for millennia. It is intriguing to consider how much the rest of the world can learn from Native approaches to health, well-being, and ways of knowing. As some Native scholars have explained:

We are living in a pivotal time in human history. Our planet, Mother Earth, is in crisis. Indigenous Peoples steward 80 percent of the world’s remaining biodiversity and, therefore, the well being of Indigenous Peoples is an explicit determinant of planetary health. The Indigenous determinants of health are not only for Indigenous Peoples but also have a benefit that is intimately connected to the future survival of all humanity and the planet. The strengths and wisdom inherent to Indigenous Peoples are “intrinsically connected to everything that exists on the planet.” This reality demands nation states, the UN, WHO, and other entities act now on the Indigenous determinants of health.

Lastly, as non-Indigenous researchers, scholars, and others learn more anticolonial research methods and start to provide essential context and background for research findings relating to American Indians, it is also important to acknowledge the critical role of Indigenous-led research and Indigenous data and sovereignty and the long overdue investments, capacity development, and policy and practice changes these require. The original inhabitants of Turtle Island have a right to nothing less.

67 An Indigenous ally is a non-Indigenous person who works in solidarity with Native communities and has established a long track record of actions that strengthen Indigenous self-determination and Indigenous ancestral practices as adapted to the present (see Appendix A to this review to learn more).

68 Redvers, Reid, Carroll, Cunningham Kain, Kobei, Menzel, Warne, Kelliher, and Roth, “Indigenous Determinants of Health.”
Appendix: Indigenous Allyship


What is an Indigenous Ally? A non-Indigenous settler who works in solidarity with Native communities and has established a long track record of actions that strengthen Indigenous self-determination and Indigenous ancestorial practices as adapted to the present.

Allies...

- recognize themselves as settlers, occupying stolen land.
- educate themselves and do not burden Indigenous Peoples with educating settlers about the violent history of settler relations with Indigenous Peoples.
- understand the role they play in, and how they continue to benefit from, continued injustice.
- do not use allyship as a self-imposed title. Allies are claimed as allies by Indigenous People;
- are not entitled to anything.
- act and communicate accordingly, as allyship is an ongoing negotiated relationship.
- work towards building trust while understanding that many Indigenous Peoples or persons will never trust them, recognizing that allies have caused much harm.
- do not claim to represent Native culture, the most aggressive form of appropriation. If you are recognized as a friend to a Native community, speak from the position of a friend.

Right Relations. To be an ally is to be in the right relationship with one another. This requires ongoing attention and care to building respectful, peaceful relations and following the lead of Indigenous Peoples. We, as settlers, already have a relationship and shared history with Indigenous Peoples. Our challenge is recognizing this relationship as it exists now, learning to establish a better one, and building a track record of constructive work to build trust.

Respect Indigenous Peoples and Cultures. Remember that you may be speaking to or learning from someone with a different worldview. You are a guest. No matter how long you are involved in a community, you, as a non-Native, are always a guest until you have been acknowledged as otherwise.

Respect looks like...

- acknowledging and thanking the Indigenous Peoples of the land where you reside or visit.
- always respecting the traditions and protocols of Indigenous ceremonies and territories.
- listening instead of speaking, especially when you are hearing criticism.
- following directions. Do it the way they told you to or was mutually agreed upon.
- not expecting that Native Peoples will be any particular way. Know that every Native person's identity is different, and each person will have their own way of being.
- understanding you are going to make mistakes. You will offend Indigenous people, and you may be harshly told so or addressed with silence. Apologize, learn, and adapt.
- looking around. Are Indigenous people in the room at work, meetings, or community events? Are they being consulted?
Ten Key Readings and Resources that Informed this Review


About the Authors

Laudan Aron is a mother to two young adults and a daughter to older adults, now in the next world, whose early lives were shaped by forced movement. Her maternal grandparents fled Iran along with other persecuted members of the Bahá’í Faith, and her paternal grandparents fled Germany along with other Jews escaping the Nazis. Conceived in Stockholm, born in London, and raised in Washington, DC, she is never quite sure how to answer where she is from. Raised by a single immigrant mother whose dreams and aspirations knew no bounds, Laudan’s early childhood was filled with rich, diverse experiences despite her family’s lack of material resources. Much of her exposure to American culture and family life came from public television (thanks to Mister Rogers and Sesame Street) and, later, TV shows she watched alone after school while doing homework until her mom came home from work. She speaks French and Farsi and is a committed lifelong learner who was educated in Oxford, England; Montréal, Canada; and Philadelphia, Pennsylvania. She is a first-generation college graduate and holds a bachelor’s degree in mathematics from McGill University and a master’s in demography from the University of Pennsylvania. In addition to her three decades of research at the Urban Institute, now as a senior fellow, she has directed studies at the National Academy of Sciences and the National Alliance on Mental Illness, both in Washington, DC.

Lizzy Ferrara is the twin sister to her brother Emilio and the only daughter to her mother, Sylvia. Despite not being of Native descent, Lizzy was raised on the Navajo Reservation, specifically in Chinle, Arizona. She grew up with her mom chasing the cows out of their garden in the morning, hiking the billy goat trails in Canyon De Chelly, splashing around in the canyon creek or the nearest monsoon mudpuddle, riding in their 1970s Volvo on day trips to get groceries, seeking out the best mutton sandwich, and attempting to wash, feed, and de-tick all of the rez puppies that landed on their trailer doorstep. As her mom was a single parent and legal aid attorney or Diné be’iiñá Nááhiiłna be Agha’diit’ahii (translated: attorneys who work for the economic revitalization of The People), Lizzy and Emilio are a product of a community effort, being partially raised by babysitters, neighbors, and coworkers. Because of a job promotion and educational opportunities, they later moved to Flagstaff, Arizona, at the base of the Dook’o’oslíd, also known as the San Francisco Peaks. Lizzy then went on to earn her bachelor’s in public health from the University of Arizona and later received her master’s in public health from Boston University. Her career centers on addressing health inequities and advocating for Native perspectives. She previously consulted for local Massachusetts public health departments and currently works as a policy analyst at the Urban Institute in Washington, DC.
About this Work

This review was written by two American researchers who are not of Native descent. Our goal has been to share resources with non-Indigenous researchers and research consumers to better understand and (re)contextualize data or discourse relating to Native people. Health and well-being must be viewed through the lens of the historical and current factors that shape them. Equally important are insights into how many Native communities conceive of health, what makes for a healthy society, and their long-standing calls for and rights to Indigenous data sovereignty.

We have sought throughout to learn from and center essential insights from Native scholars, leaders, defenders, and knowledge keepers. Much of what we learned transcends Native communities and even human health, holding significance for all life on this planet.

Throughout this review, we use the terms Native Americans, Indigenous Americans, and American Indians to refer to the same large group of people, recognizing that whenever possible, many Native people prefer to be called by their specific tribal name, recognizing and honoring their unique heritage.

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