NCUIH on PBS: Why Indigenous people in cities feel invisible as pandemic wears on

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Like many other communities of color, Indigenous people across America have been disproportionately affected by the coronavirus because of historical health disparities, lack of basic resources in some parts of the country and poorly funded Indigenous health care.

Navajo Nation, the largest American tribe with more than 300,000 members, has been devastated by loss. As of February 21, at least 1,144 Navajo people have died from the virus. Centers for Disease Control race data from December in 14 states show COVID-19 mortality among American Indians/Alaska natives was 1.8 times higher than white people. In another study of data from 23 states last summer, American Indians/Alaska Natives tested positive for COVID-19 three and a half times the rate white people tested positive.

As COVID-19 began ripping through Reva Stewart's Navajo Nation community, she started localized community help through an Indigneous store in Phoenix, delivering and making hundreds of care boxes. And then her worst fear came true.

After months of being careful, Stewart's daughter, Raven, started feeling sick with COVID-19 symptoms over the summer.

"She's 24, has asthma, low iron levels, and underlying issues, and I was so scared," Stewart said.

Raven was the third person in Stewart's Phoenix-based family who became infected with the coronavirus in June. Stewart moved from the Navajo reservation to Phoenix decades ago to pursue her schooling to work in health care. She tries to go back on the reservation on occasion to help her extended family.

"I've lost two aunties, three uncles and a couple of cousins," Stewart said. "It's sad because you can't go to the funeral service. I can't get up and travel to be with family."

As COVID-19 has swept through Navajo lands, the tribal government enforces lockdowns and curfews, sometimes for weeks at a time. These measures are meant to stop the spread of the virus in a place where most of its residents have to drive long distances for their jobs, to haul water and to get groceries. The checkpoints set up by Navajo police also discouraged outside visitors to come into the area in an effort to contain COVID-19.

But according to census data, more than three quarters of the country's Indigenous people don't live on designated tribal lands. More than half of all American Indians live in cities. According to the Indian Health Service, at least 6,766 Indigenous people in urban areas tested positive for COVID-19 from the beginning of the pandemic in March 2020 to mid-February.

The Phoenix metropolitan area has the third-highest American Indian population in the country, after New York City and Los Angeles. Indigenous people also make up about 4 percent of the COVID-19 cases in Phoenix metro. The data also show that cases and hospitalizations rates for Indigenous people are double the total population in Maricopa County which encompasses Phoenix,

one of the largest counties in the country.

When Stewart's older daughter, Michelle, had symptoms that quickly deteriorated to the point where she felt like she couldn't breathe and called 911, she was taken to a Phoenix hospital. The hospital found she had a 104 degree temperature and low oxygen levels, but released her from the emergency room after an hour of treatment.

"She said the security guard said she couldn't wait in the front and had to get off the campus because she was COVID-19 positive, and had to wait down the street away from the hospital in the [100-degree] heat," Stewart said. A hospital spokeswoman told PBS NewsHour it's their policy to keep COVID-19 patients in the emergency room until their ride arrives.

Stewart was furious and terrified, as her two daughters and their father were now sick at the same time.

"I started to hyperventilate," she said. "I put plastic everywhere, doubled up my mask, picked her up and didn't want to scare her, but I was scared too."

By July, Stewart said she was grateful they were all doing better, despite some lingering symptoms. "It was really stressful and scary."

For American Indians living in urban settings, like Stewart, the Indian Health Service offers health care through more than 40 nonprofit health programs, called Urban Indian Organization facilities or UIO. These are not directly funded through federal money, but rather through IHS grants. Stewart's daughter was not taken to an IHS facility like the Phoenix Indian Medical Center, which frustrated Reva.

'Urban Indians are invisible'

"In general… urban Indians are invisible. A lot of times our urban Indian organizations may be missed," said Dr. Rose Weahkee, acting director of the Office of Urban Indian Health Programs. "They're an integral part to the IHS system. They provide culturally appropriate, quality health care to our Indian patients and are a safety net for families living off the reservation who want to maintain ties to cultural traditions, which is important when addressing COVID-19."

Weahkee, who is a member of the Navajo Nation, said about $103 million from CARES Act funding is going to help urban Indian centers, with about half of that money going to COVID-19 testing. She also said the IHS has done outreach with urban Indigenous people to understand their specific concerns better.

"One way we wanted to get those urban needs is have the Indian Health Service director hold biweekly calls with urban Indian center leaders so the IHS can help provide updates, clinical guidance and testing data," she said. "It's also an opportunity to hear from urban programs on what their priorities are and needs and concerns."

One concern is underreported COVID-19 positivity rates. While IHS hospitals on tribal lands often have the knowledge and resources to keep more complete racial data, tribes and urban Indian centers are not required to share their COVID-19 testing data on the federal level. That can lead to gaps in racial health data.

Abigail Echo-Hawk, director of tribal epidemiology center Urban Indian Health Institute in Seattle, worries the COVID-19 positivity numbers in urban Indigenous communities do not tell the whole story.

“From the limited data that we do have, we are seeing a disproportionate impact… our community is seeing and having higher rates of positive COVID tests,” Echo-Hawk said. “But we know that is a gross underreport. If we had the real data, I think that that disparity would be much higher.”

Echo-Hawk, who is Pawnee, said the best data on Indigenous people is typically collected on the reservations and by Indian Health Service facilities. Non-tribal entities, like hospitals, cities and counties, don’t always follow the best data collection practices for identifying someone’s race, Echo-Hawk said. Data is especially vulnerable for mixed-race people, which is the case for many Indigenous people.

“When you go into a clinic waiting room or your family fills out forms for you, they may not even have the box that says ‘check this box to identify as American Indian or Alaska native,’” she said. “Another problem is that we find a lot of people may be uncomfortable asking somebody’s race and ethnicity. For American Indian/Alaska native people, we are one of the highest-growing groups of multi-race individuals. So there is no specific look, no specific skin color. We need to be asked the questions.”

The Urban Indian Health Institute recently released a report grading each state on its COVID-19 data collection when it comes to complete Indigenous records. The average was a D+. More than a dozen states failed the assessment, which took into account whether the state includes American Indian/Alaska Native as a population on its data dashboards

> “We know who we are, and these are our homelands,” Hawk Lessard said. “So to be rendered invisible is another incidence of historical trauma, but it also conveys that our worth as ‘other’ is OK.”

The states with the highest grades were Minnesota and Vermont, with Texas coming in last.Historically, racial misclassification is rampant in Indigenous medical and death records. According to the National Council of Urban Indian Health, almost half of people who self-identified as American Indian or Alaska Native — the federal classification of Indigenous races — were classified as white on their death certificates. Some hospitals also fail to gather or correctly record an Indigenous person’s health because paperwork during COVID-19 is done under time pressure, and social distancing precautions means fewer discussions between families and data collectors or health professionals.Stewart said she does not recall anyone asking for her race when she got a coronavirus test at an Honor Health facility in downtown Phoenix. Providers did ask at Phoenix Indian Medical center when her family did tests at that hospital which is funded by the Indian Health Service (IHS).

Hope in the vaccine

COVID-19 vaccines are now being distributed within tribes, including the Navajo Nation, as well as through the UIO programs in cities. It’s a spark of hope for communities that have historically felt left behind in epidemic response plans, including during the vaccine rollout for the H1N1 swine flu — a virus that killed Indigenous people at a rate four times more than the rest of the country. The National Council of Urban Indian Health said in a letter that “access to and/or a distribution plan for [H1N1] vaccines were afforded last, if at all,” in Indigenous communities.

The vaccines will go a long way to lower positivity rates and the secondary effects of the pandemic, said Dr. Weahkee. She said IHS has also heard of a surge in behavioral health problems, like domestic abuse and misusing substances. CDC numbers show the pandemic has exacerbated the suffering of Americans struggling with substance use. Drug overdose deaths have reached historic

highs.

Many urban Indigenous programs do outreach specifically aimed at behavioral health problems. But the programs don't exist everywhere.

Most of the American Indian population lives in the West, but those living on the East Coast also face problems with COVID-19.

> "Sometimes we're seen as those 'poor Indians,'" Wanda Frenchman said. "We're educated, we're employed, we're homeowners, we're not the kind of Indians who are struggling. Maybe that's why they don't see us, as we have been able to assimilate to the mainstream."

Indigenous people who don't live on reservations, like Faith Begay Dominique who lives in Washington D.C., say they feel helpless as they watch from afar as the virus rips through their tribes. Begay Dominique is originally from the Lower Brule Sioux tribe reservation in South Dakota. She is also Rose Bud Sioux and Navajo.

"My uncle on my dad's side lives in Arizona and passed away from COVID, so that's been really hard and heartbreaking to me," she said. "He was the vice chairman of the Cocopah Indian Tribe and would come to D.C. a lot. It's really hard being out here without any family, and it was always nice to see him. I'm completely heartbroken he passed away."

She and her wife both caught COVID-19 in late March. Begay Dominique said she never got tested or went to the hospital. Her wife, who is not Indigenous, had worse symptoms and was able to get tested because she works in health care.

With no record from a test, Begay Dominique's likely COVID-19 infection as an Indigenous person would be uncounted in official data sets, both where she lives in Washington D.C. and on her reservation back in South Dakota. She is likely one of many urban-dwelling Indigenous people that are not being added to the increasing caseload of COVID-19 affected Indigenous people, according to Kerry Hawk Lessard, a member of the Shawnee people and the director of Native American Lifelines in Baltimore — the closest urban Indian health option to Begay Dominique.

"Baltimore city, that's a big area for Native people," she said. "I personally know people who have been tested and one person who has tested positive. But our community members don't show up in the data. Everything adds insult to injury."

As of February, Baltimore data show 123 American Indian people testing positive for COVID-19, but more than 8,000 cases are categorized as "unknown" or "other" ethnicity.

Additionally, Maryland state government doesn't use American Indian as a race category in official COVID-19 data, one of 14 states that don't publicly keep track of that data.

"We know who we are, and these are our homelands," Hawk Lessard said. "So to be rendered invisible is another incidence of historical trauma, but it also conveys that our worth as 'other' is OK."

Most Indigenous Americans don't live on a reservation

In the mid 20th century, a commission found the Bureau of Indian Affairs relocated over 160,000

Indigenous people to different urban centers across America. The original goal was to move Indigenous people off reservations into cities, like San Francisco or Salt Lake City, where there was a promise of more jobs and a better life. The attempt at assimilation was not well-supported by the BIA, leaving stranded Indigenous people with culture shock and little economic opportunity.

Wanda Frenchman said her parents, who are Pine Ridge Lakota from South Dakota and Lenape from Delaware, were relocated through this program to Arizona. Her partner is Navajo and they travel up to the Navajo Nation as often as they can to help his family and friends, many of whom have died from COVID-19.

“It’s almost every week we hear someone else passing away,” she said. “What I’m seeing is we [in the urban areas] are not suffering anywhere near the degree the people on the reservation are, and I hate to say it, but the attention is where it’s needed because they are suffering and the numbers are so high.”

Frenchman said when she and her partner got tested for COVID-19 in a testing blitz back in March, officials asked for an ID and their address, but did not ask questions about demographic data.

While she is grateful to be healthy, Frenchman understands how Indigenous people in urban areas feel overlooked.

“Sometimes we’re seen as those ‘poor Indians,’” she said. “We’re educated, we’re employed, we’re homeowners, we’re not the kind of Indians who are struggling. Maybe that’s why they don’t see us, as we have been able to assimilate to the mainstream.”

Frenchman uses the IHS facilities near her, because the health care is free. She got her first COVID-19 vaccine dose at Phoenix Indian Medical Center in January. But many of those urban facilities with Indigenous-specific resources had to close early in the pandemic, leaving a vital resource more difficult to reach for urban Indigenous people. All 41 UIOs now are providing services.

Native Health in Phoenix, which provides health care, dental and behavioral health services to urban Indigenous people, was one of those facilities that had to close in-person services for some time during the pandemic. Now, the UIO is open and providing services for the community. Native Health CEO Walter Murillo, a member of the Choctaw nation of Oklahoma, said understanding Indigenous culture is key to providing the best health options for people if they live off the reservations.

“Being isolated within a city of 3 million is a real thing for American Indians,” Murillo said. “How do you maintain culture, language and a sense of community? We’re surrounded by people, but they’re people of different cultures and even health conditions.”

Murillo said Native Health was part of the statewide testing blitzes when Arizona was a COVID-19 hot spot in early summer of 2020. But in some of those fast-paced testing efforts, race data is missing.

In Arizona, almost a fifth of positive COVID-19 cases were unknown race or ethnicity.

Fewer federal funds

The data is also murky in neighboring California, where 90% of Indigenous people live in urban areas, according to Virginia Hedrick, executive director of California Consortium for Urban Indian Health (CCUIH), a statewide health outreach program.

“We have such an information gap in who is the most vulnerable,” she said. “One thing about public health and infectious disease is you need all the information you can get to make decisions. For example, who are the people that have passed from COVID-19, were they diabetic or old? Is it the 18-30 age group testing positive?”

Hedrick, who is Yurok/Karuk, said that because data for Indigenous health isn’t being adequately tracked, there are fewer chances for data-based federal funding to help, leaving the tribes who have been hit hardest to pick up the pieces.

Many urban Indian organizations, like Hedrick’s, also say they need more resources.

“Urban Indian Health programs, at the federal level, are deeply underfunded. We have to get other funding, and work within our networks, to get the PPE (personal protective equipment) we need,” she said.

Stewart, in Phoenix, said she’s decided to take it into her own hands to help anyone getting sick with COVID-19. Almost every day, she posts on a Facebook group for urban Indigenous people in Phoenix, offering care boxes with chicken broth and hand wipes, as well as traditional Navajo natural objects, like flat cedar and herbal tobacco.

She takes donations at Indigenous-focused Drumbeat Indian Arts store, now converted into a hub for urban Indigenous people in the city looking for help.

“While we were working at the store [early in the pandemic], I had a young lady come ask for sage and she was in tears,” Stewart said. “I said ‘are you OK?’ She said, ‘My whole family has [COVID-19].’”

She said she’s made and delivered hundreds of care boxes.

“I’ve met tons of people doing the same thing. It’s not just me, it’s so many people trying to help the [Navajo] reservation,” she said. “But we need to help our own people down here. And that is why I haven’t stopped.”