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Fighting the COVID-19 Merciless Monster

Lives on the Line—Community Health Representatives' Roles in the Pandemic Battle on the Navajo Nation

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Abstract: Over 100 Community Health Representatives (CHRs) as part of the oldest and largest Community Health Worker (CHW) program in the United States serve the Dine People on the Navajo Nation. The CHRs work under a tribally determined scope of practice that embraces the importance of self-determination of tribal nations, a philosophy central to the CHW field nationally. Navajo CHRs are the epitome of frontline workers, as they extend their traditional role to encompass long-term emergency response during coronavirus disease-2019 (COVID-19). This article describes the Navajo CHR role in the pandemic through the lens of an interview with the program's director, Mae-Gilene Begay**.** **Key words:** *American Indian, community health representative, Community Health Worker, COVID-19, Native American, Navajo, roles, scope of work, self-determination, workforce*

MAE-GILENE BEGAY, the Director of the Navajo Nation Community Health Representative (CHR) Program, has just gotten back from staffing a curfew checkpoint when we get her on the phone. The CHRs have been helping the police at the roadblocks by providing coronavirus disease-2019 (COVID-19) education and information to the passersby. She recounts a story of a COVID-positive patient they encountered that day. "This individual had run out of needed supplies and was very emotional, so the CHR stepped aside to take care of that," she said. "The traveler had been told to self-isolate but ran out of food and she needed to get something to eat and she was out of water. She had to leave her house to get supplies."

This is today's reality for many on the Navajo Nation, an expansive and rural community where a good percentage of families still haul water and the nearest grocery store is often hours away. And in a community where multigenerational homes are traditional, with family members providing mutual care between children, adults, and elders—this has made physical isolation difficult as younger household members leave home to work or drive hours in a car with neighbors or family members to get provisions from the closest store.

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Much has been publicized in the last few months about how the devastating rates of COVID-19 in the Navajo Nation reflect systemic racism and inequities in the development of health systems, access, the capacity for regional response, and the inconsistent federal response (Goldfield, 2020; Kristof, 2020). However, insufficient light has been shone on the strength and resolve of the CHRs (part of the broader Community Health Worker (CHW) workforce), as they shift to meet the needs of their communities. Over 100 Diné women and men have gone above and beyond their traditional roles of serving as health promoters and a bridge between tribal members and health care team members to work in crisis management roles. CHRs are helping to carry out tribal mandates such as routine curfews; they are delivering medicine, food, and cooking supplies to individuals and families in quarantine, translating COVID-19 health directives and related materials, and connecting people to support resources to aid them as they work to socially distance. This new long-term emergency response is carried out while their own lives are affected by the disproportionately high infection and mortality rates in their community and families.

In this article, we worked with Mae-Gilene Begay to tell the story of what Mae-Gilene calls "merciless monster" of COVID-19 and the CHR effort to help mitigate its impact on the Diné people. Mae-Gilene Begay is a lifelong member and resident of the Navajo Nation and has worked as the CHR Director for 20 years. She is a national leader in the CHW field, having served as the Chair for the American Public Health Association's CHW Section and a founding board member of the National Association of Community Health Workers (NACHW, 2020).

THE EVOLVING ROLES OF CHRS DURING COVID-19

For decades CHWs throughout the United States and globally have been a backbone for underserved populations, providing both preventive and occasionally primary care to their neighbors and communities (World Health Organization, 2020). The CHR program in Indian Country is the oldest and largest CHW program in the United States, serving residents of Arizona, New Mexico, and Utah. The program started in the 1960s, building on the philosophy of the War on Poverty and extending meaningful work opportunities to tribal community members. The mission goes beyond traditional workforce development, leaning into tribal self-determination by asking tribal leadership to select CHRs and define their scope of practice. In years past, oversight, training and capacity building for CHRs was managed nationally by the Indian Health Service but now 95% of CHR programs, including the Navajo program, have shifted to full leadership by their respective tribes (Indian Health Service, 2020).

Key to the public health response to COVID-19, CHRs have been working within their full scope of practice, using their well-established roles and skills that align with the CHWs throughout the United States (Rosenthal et al., 2018; Rosenthal & Fox, 2017) while developing new roles to meet the current challenge. CHRs are reinforcing their roles as cultural mediators, or liaisons, and health educators. Mae-Gilene explains, "Some patients are intimidated asking their doctors questions so they leave without a full picture of their diagnoses or what they should do. The CHRs speak to them in their language and they open up, so the CHRs get more of a picture of the gaps in their knowledge about COVID-19. They ensure that community members receive discharge orders in their native language and they explain public health protocols with dignity and respect."

While CHRs' scopes of work closely align with the traditional roles and competencies of CHWs, they often perform more clinical tasks such as screenings, preventative examinations, and first-aid care than other US CHWs outside of tribal settings (Sabo et al., 2019). Mae-Gilene observes this has been a distinct advantage during the COVID-19 response, as they have been able to help alleviate the pressure for patients with chronic health needs and the overstressed health care system. "There are long standing shortages

of providers in our area. We have been proactive with the program to see how CHRs can get a little bit of training in medical skills to be an extender of the healthcare system." All CHRs on the Navajo Nation are Certified Nurse Aids and most are trained as CHWs with the New Mexico Department of Health. They have also been certified as Community Dental Aids in a collaborative project with the American Dental Association and they regularly respond to short-term emergencies on the Nation, such as natural disasters.

During the current response, however, Mae-Gilene explains that the CHRs' roles encompass more than ever before. "The CHRs are doing so much work—often until late at night and on the weekend. At the beginning, they were delivering things while having very little PPE, but they were determined to get resources to the people who needed it most. Some of the tribal members we serve are going through depression, getting anxiety attacks, just worrying . . . so they (the CHRs) have to do some social work related counselling and do a lot of referrals to various mental health agencies. CHRs are able to quickly identify the most vulnerable and underserved members of their community and ensure resources make it to the families that need them."

The CHRs have been a critical force in the contact tracing response on the Nation, another new role for the workforce. "CHRs are well suited for contact tracing and are able to fit it in easily to their existing work," said Mae-Gilene. "They are tenacious and don't give up when a contact's phone number doesn't work—they often know the patient and where they live so they go to the home, bringing with them medicine and other supplies that family needs to be able to care for their family members and stay home and quarantined."

The road has not been easy for the CHRs, as many of them face similar barriers to access and similar living situations as their patients. Our team has been proactive in response to COVID 19 exposures, taking required time off when needed and then getting right back to work. "There is grief as we lose relatives and patients to COVID. CHRs are working on nights and weekends. It is hard work but they are all doing it so willingly and with passion and care because they truly want to care for their communities. The pandemic is a learning experience. At this time we're going on four months of emergency-level response. It's new but we have the skills and the desire to do the work."

Despite it all, Mae-Gilene is hopeful about the future both of the Navajo Nation and the CHR workforce. "Navajo Nation and CHRs built resiliency in the way we were brought up and raised. This situation has raised awareness and appreciation of the work CHRs do and I hope more people on the Nation will get interested in the field," she said. "When this is done, we will need to deal with the grief using both traditional and western healing. For now, we are focusing on putting our training into practice and putting our lives on the line."

CHRS, SELF-DETERMINATION, AND THE NATIONAL CHW LANDSCAPE

Mentions of police, curfews, and checkpoints might bring up images of confrontation and violence. However, as Navajo public health and safety staff, including CHRs, work together under the coordination of Incident Command, they are joined in a common purpose, to protect and care for their neighbors. "When the CHRs spoke with the motorist who had COVID-19 about her lack of water and food, they worked with her to identify resources where she could safely go to replenish her supplies and get home again to continue to honor the curfew." According to Native American health activist Michael Bird, this approach to caring for the community would seem to reflect how tribal members equate self-care with caring for others. Bird (2002) writes:

> Personal responsibility for indigenous people recognizes relationships and connections to others (family, tribe, community, world community). If I am to do well, then others must also do well. I am not isolated in thought, deed, or action. All are related and interconnected. I am personally responsible; I am my brother's keeper. (Bird, 2002, p. 1392)

Mae-Gilene refers to the CHRs as the most trusted health care provider on the Navajo Nation. Many community members trust them more than they trust their physicians. This extends to municipal leaders at their chapter houses, who have looked to CHRs for leadership and insight during the COVID-19 response. Mae-Gilene shares that "The chapter officials ask CHRs what the community needs before they purchase the food boxes or supplies because of their intimate knowledge of the needs of individuals across their community." The CHR COVID-19 response has been community-driven, centered around the insight of the CHR workforce, itself selected and shaped by community assets and needs. The CHR scopes and priorities are set by the tribes while the insight gained through their work is shared back with the leaders, like a bidirectional circle of support and leadership. Their implementation of self-determination stands as a model for the CHW workforce as a whole.

When commenting on the necessity and success of the Navajo Nation CHR Program and the value of their self-determined programmatic scope, it is worthwhile to consider the program in the current national context of the CHW field. CHWs have come into a new light during the COVID-19 pandemic as members of the frontline public health workforce who are able to reach underserved communities disproportionately impacted by the pandemic. Their capacity has not gone unnoticed—there are recent calls for action to support CHWs and to assure standards of their training and competence. The American Public Health Association's foundational resolution that recommends 50% CHW representation in any CHW workforce initiative is as important as ever, as the CHW field gains visibility and support during these unprecedented times. The NACHW, launched in 2019, provides a space for important CHW-led advocacy for the CHW workforce and for CHW-led efforts to define and develop their field. Other foundational work has recently culminated in CHW-informed and partnered national initiatives, including the Community Health Worker Core Consensus (C3) Project cited earlier for its work on CHW core roles and competencies and also the Common Indicators (CI) Project on CHW evaluation strategies (Wiggins et al., 2016). The self-determination of the CHR program on the Navajo Nation sets the bar high for community-directed and centered care and can inform resurging efforts to promote this community-based and tailored approach to community health.

Examining the CHR program's role during the pandemic reminds us that solutions to problems, whether external or internal, are best led by members of the communities impacted (McKnight, 1996). We propose that we work together to preserve and strengthen these locally based self-determined programs not only in tribal communities but all communities across the United States where priorities can be defined and addressed by community members in partnership with outside collaborators. Promoting and listening to the voice of such local, grassroots leadership can help to ensure that services we provide and infrastructure we develop have the maximum beneficial outcomes for all concerned. The COVID-19 pandemic has given us an opportunity to see both the strengths and the deficits of our current systems and capacities and point the way toward a new direction. Where we go next in this new era must include community-centered care to address violence, illness, and poverty that confront the global community. As Goldfield et al. (2020) discuss, in their article, it is time to put CHWs at the center of the spoke in a paradigm shift, prioritizing community-driven solutions to both prevent and treat chronic and infectious diseases like COVID-19.

The COVID-19-positive motorist at the curfew checkpoint on the Navajo Nation received valuable emotional support and critical basic necessities like water, food, and medicine from the CHRs, one of many lives touched by them that weekend. Mae-Gilene explains, "Some of the CHRs have been going and going. Many of the CHRs were working yesterday and today at the checkpoints and will be back at work on Monday. When we get 500 boxes of perishable food donations, we have no choice but to distribute all 500

within 24 hours ... Right now we're not able to slow down. We just have to get our rest overnight and just keep going. They are the frontline warriors and they are fighting the Merciless Monster tirelessly—as CHRs have always done in order to win for their people."

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