“Nothing About Us Without Us”: Best Practices Learned Through Supporting Community Health Workers in Hawai‘i Nei and Beyond

Napualani Spock MA, MBA and Ashley Wennerstrom PhD, MPH

Abbreviations

APHA = American Public Health Association
AHEC = Hawai‘i-Pacific Basin Area Health Education Center
CHW = community health worker
HPCA = Hawai‘i Primary Care Association
RDP = Hawai‘i Rural Development Program
LACHON = Louisiana Community Health Outreach Network
NACHW = National Association of Community Health Workers
UH = University of Hawai‘i
WCCHC = Wai‘anae Coast Comprehensive Health Center

Background

The purpose of this editorial is to illustrate important lessons that we have learned while working as community health workers (CHWs), or with CHWs, over the past 20 years nationally and in Hawai‘i. We describe our personal and professional encounters with the CHW movement over time, and share the values of the CHW movement and why these are important. We hope this editorial can provide useful, real-world histories from our lived experience to accompany the academic articles in this special issue and can help frame the discussion of CHW engagement and empowerment going forward.

Napualani Spock’s Story

Introduction to CHWs

I first encountered CHWs in practice when I attended an event held by *Hui No Ke Ola Pono*, the Native Hawaiian Health Care System for Maui, with my mother and her friend Auntie Theresa at a church in Lahaina around 1996. We were greeted warmly and familiarly by kind people who introduced themselves as Joey and Auntie Aloha. They did an intake with my mother and Auntie Theresa and collected many vital health metrics: blood pressure, blood sugar, body mass index, survey of dietary choices and physical activity habits, tobacco and alcohol use screening, and a mental health screening. Then Auntie Ulu, the exercise teacher, led a hula-cize class, which I joined. After hula, we were treated to a healthy dinner of Hawaiian food (*poi*, chicken *laulau*, *limu*, and *lomi* salmon). There was a short lecture about the impact of colonialism on our health, and an exhortation to return to our traditional healthy lifestyle practices. This entire experience around health and wellbeing was done in a culturally-appropriate manner for the Hawaiian community. The staff were humble and respectful to the elders (including my mother and Auntie Theresa), encouraging, positive, and careful not to induce any shame about body weight or fitness levels, something the elders would likely have encountered in a common gym. It felt good to be there with these people, like being with family who know how to talk with you, sincerely love you, and want to support your health and well-being.

In 2000, I was hired to work at that same organization, *Hui No Ke Ola Pono*. I met Joey, Auntie Aloha, and Auntie Ulu again, now as coworkers. My job was a new position, named community health coordinator. I was charged with helping to create a community learning center that would be co-sponsored by the Hawai‘i-Pacific Basin Area Health Education Center (AHEC) and to develop a new stroke prevention program which would be client-centered and reflect Hawaiian values. I came from the Hawaiian language/Hawaiian studies community so I was requested to help integrate our Hawaiian culture into the public health promotion program. In this role, I was now a CHW, although I did not yet know to call myself that.

Over the course of 2 years in this role, I learned so much from my fellow CHWs—their loving familial approach to our clients (everyone was “auntie” or “uncle” and treated with reverence), what issues our clients had and what resources were available to meet their needs in our Maui community (from food, to housing to health insurance), how to engage community partners to create an authentically-community-responsive program, fundraising, working with community advisory committees, and working with grant makers. I was taught that funders are not looking to offer handouts, but rather to partner with community organizations to achieve mutual goals. As such, it is the responsibility of the community organizations, as experts on their community, to ensure that resulting programs are culturally-appropriate and effective. If maintaining a culturally-appropriate approach would require modifying the methods of a funder’s proposal, it is important for the community organization to advocate for the modifications.

My job with *Hui No Ke Ola Pono* was a full-immersion education in community health and program design for me. Our CHW team reflected the community we served. I saw my own family members mirrored in the families we served, and knew inherently how to communicate effectively, what clients valued, how to best approach them to support the public health goals of improving Native Hawaiian health. They (we) WERE the community being served, as well as the people doing the serving. Therefore, as CHWs engage with the community, there is an easy, insider rapport that develops naturally and easy recognition of issues, concerns and nonverbal signals that would otherwise be missed. CHWs know that auntie is not answering truthfully about whether she is taking her medication daily because she has had to prioritize feeding the grandchildren she is fostering, but she would not say this because she would be embarrassed

on so many levels. Also auntie would be more likely to share this information with a CHW who would understand the subtle cues quickly without interrogating or judging. These lessons remained with me throughout the 20-year career that followed, while I worked as a CHW and supported and trained other CHWs.

The CHW Movement

In 2002, I was recruited to coordinate the development of a CHW training program at the Hawai'i Primary Care Association (HPCA) in collaboration with the University of Hawai'i (UH) Community Colleges. My first task was to establish a community advisory committee to help guide the curriculum development process and ensure that it would address the needs of CHWs and their employers across the state. We sought to tailor the training to meet the workforce development concerns of the statewide network of community health centers and Native Hawaiian Health Care Systems (like *Hui No Ke Ola Pono*) on every island.

I first had to figure out what a CHW actually was. How was this role defined? What were the boundaries? What were the job descriptions? I asked around. There were no such job titles at the agencies I was serving except for Wai'anae Coast Comprehensive Health Center (WCCHC). I visited and interviewed staff of WCCHC's Health Academy. They shared the curriculum they developed specific to the needs of their health center. I also reached out to other workforce development entities, including partners on previous projects such as Hawai'i-Pacific Basin AHEC and *Papa Ola Lokahi*. AHEC's Director, Dr. Kelley Withy, had heard about CHWs in one of her National AHEC meetings, and she introduced me to CHW researchers she knew. Dr. Don Proulx and Dr. Lee Rosenthal had worked together on The Community Health Advisor Study, the first published national iteration of core roles and competencies of CHW in 1998. This project provided valuable curriculum development resources, explained the distinctions between certification and credentialing and encouraged me to attend a national CHW conference hosted by the University of Southern Mississippi Center for Sustainable Health Outreach, called "Unity."

The 2002 Unity conference was held in Biloxi, Mississippi. It was an amazing opportunity and eye-opening experience. There I was, for the first time, surrounded by people who were community activists applying social justice values in service to their communities. The diversity was inspiring — people from so many communities across America from Native American, Amish, LGBTQ, African American, immigrant and Spanish-speaking communities. Within the diversity, there was a palpable unity of purpose and spirit! I felt I had found my people! They were all serving their communities, the communities they came from themselves, in a culturally-relevant, authentic way to promote social justice and improve social determinants of health whether they were called *promotores,* community health representatives, outreach workers, lay health educators, or any number of other titles. It was here that I learned about the larger CHW "movement."

At that first conference, I was the only Hawaiian attendee. Over the years, the number of Hawai'i participants has grown. At the 2019 conference in Las Vegas, more than 25 people from Hawai'i were in attendance! Together we learned about this growing movement and the values it found to be most helpful in supporting community health workers and their maximum effectiveness in addressing social determinants of health in their respective communities.

CHW Training Programs

Back home in Hawai'i, after the first Unity Conference in 2002, our HPCA CHW Community Advisory Committee sought to integrate what we learned from the national experts into our homegrown community expertise. Together with our partners we developed 2 CHW training programs, which were offered through the UH Community Colleges and funded through the Federal Department of Labor's subcontractee, the Hawai'i Rural Development Program (RDP).

In 2002, we started with a 9-credit Certificate in Case Management program, named for function rather than job title because of the lack of name recognition for the term CHW at the time. This program included 3 basic courses: Individual Counseling, Case Management, and a practicum. We were given a second RDP grant in 2004-2006 to develop training to address the next area of priority need: outreach strategies, health promotion/disease prevention, and community advocacy. Through this process, we developed a 100-hour Certificate in Outreach for Health Promotion, comprised of 3 credits plus 55 hours of seminars taught by rotating content-area specialists who believed in the CHW model, could serve as mentors and career contacts, and knew how to teach adult learners effectively. Both certificate programs were delivered across the state by local lecturers affiliated with local community colleges on Kaua'i, O'ahu, Maui, Moloka'i, and Hawai'i. Hiring the same instructors for both programs promoted the sustainability of the programs. We engaged the members of our statewide Community Advisory Committee to identify potential instructors, determine appropriate class schedules, and recruit participants on their respective islands to populate the classes. We also identified additional CHW leaders in each class to help facilitate sign-in and other logistical considerations.

More than 150 people completed one or both certificates during the 4-year period of 2002-2006. Many of these CHWs remain in service at community health centers, Native Hawaiian Health Care Systems, and other health and human service agencies today. Community networking and engaging local community-based partners was the key to reaching our lofty goals. Local CHWs, their employers, and the local organizations know their own communities best and can spread the word about training and help with identifying partners and resources better than any outsiders.

In 2014, I was hired at UH Maui to help write a workforce development grant which would focus on CHWs and School Health Aids, as newly-formalizing workforces. We strived to build upon previous efforts so that the many students who

completed previous certificate programs would not have to start from scratch. Through this grant, we developed a 15-credit certificate program that included the 9 credits from the Case Management Certificate as well as the topics which had been covered in the 100-hour Certificate in Outreach for Health Promotion (updated and adapted as CHW 101 and Health Promotion/Disease Prevention). Students who had previously taken the 9-credit Case Management Certificate needed only to add the CHW 101 and Health Promotion/Disease Prevention (6 credits) in order to obtain the new CHW Certificate.

In the meantime, so much had happened on the national level that increased awareness of CHWs as valuable, essential members of the public health team with the most potential to impact social determinants of health in underserved and vulnerable populations that many new stakeholders emerged in Hawai'i to support CHWs. Throughout the entire process of working with CHWs all these years, our strategy has been to partner with local CHWs, their employers and local community colleges, invite them to engage with us in a meaningful way to assess and prioritize needs, generate solutions, and provide continuous feedback to ensure the most relevant, desirable, effective programs.

Ashley Wennerstrom's Story

Introduction to CHWs

I first discovered the magic of CHWs in 2006 when I was a public health student at the University of Arizona. One of my incredible mentors, Jill Guernsey de Zapien, invited me to a bi-national training for CHWs working on both sides of the United States-Mexico border. As the participants went through an exercise in which they used a paper tree taped to a wall to identify the root causes of health problems, I realized that this health workforce was special. They did not deal in clinical work or technical terms, but it was clear that they intrinsically understood how social inequities shaped health in a way that many health care professionals did not.

A couple of years later, I accepted a position in post-Katrina New Orleans that was focused on building local mental health services delivery capacity. One element of the work involved training and supporting CHWs to do outreach and education about depression, and to make referrals for services. Again, I saw that CHWs were unique in that they could effectively address a highly stigmatized health issue in a way that other health care providers could not. They could connect with people who had been through trauma and make them feel safe enough to ask for support.

When that project concluded, several CHW colleagues and I went on to develop a CHW workforce training program, as well as a CHW professional group called the Louisiana Community Health Outreach Network (LACHON). Our goals were to develop local capacity to help new CHWs enter the workforce and to support existing CHWs who often work under very stressful conditions. As my longtime colleague and friend, Catherine Haywood, always says, we created LACHON because "CHWs need a place to vent." Today, under Catherine's dedicated leadership, LACHON is playing a vital role in uniting CHWs across Louisiana and advising the state on CHW workforce policy.

The Question Is No Longer Whether to Engage CHWs, but How To Do So

During the last decade plus of collaborating with CHWS locally and nationally in various capacities, such as implementing interventions, conducting research, and developing policy, we have encountered numerous questions from policymakers, health care providers, and administrators about whether CHWs are effective. In the last few years, though, the conversation has shifted. The evidence base on the value of CHWs has grown tremendously and multiple federal agencies now recognize the importance of CHWs. Stakeholders are no longer asking whether to engage CHWs in the health systems transformation, but rather how to do so.

This monumental shift could not have happened without CHWs organizing for themselves. For example, one of the most important developments in the CHW world was simply settling on the term CHW as an umbrella title for many jobs and defining the CHW role. Thanks to organizing by members of the American Public Health Association (APHA) CHW section, APHA adopted a definition of CHWs in 2009,[1] and this definition has since been embraced by many CHW professional groups around the country. Members of the APHA section advocated for CHWs to be included as members of health care team in the Affordable Care Act and to have the United States Department of Labor create a new standard occupational classification for CHWs so that members of the workforce could be counted as such. Some individual states have begun to develop policies aimed at expanding the CHW workforce, and in response to concerns that such policies might be dictated by people other than CHWs, that APHA CHW Section successfully advocated for the organization to adopt a policy stating that at least half of the members of all bodies creating CHW workforce policies should be CHWs.[2]

The National Association of Community Health Workers

Perhaps one of the most exciting recent development in the CHW world, and one that we have been honored to play a small part in, has been the creation of the National Association of Community Health Workers (NACHW). For 3 years, roughly 20 CHWs and allies have worked to develop what we believe will become a single national voice for CHWs. Based on the lessons we have all learned in our home states and through national organizing work, particularly through the APHA CHW Section, we created a set of values including unity, self-empowerment, self-determination, social justice, equity, integrity, dignity, and respect, by which we will operate our organization. We officially launched the organization at the Unity Conference in Las Vegas with other 900 CHWs from across the country in attendance.

Conclusions

Throughout our decades of work, one of the most important lessons we have learned is the value of CHW leadership. In the

case of Hawai'i, we have supported community-building and leadership development on all 8 islands in the state because CHWs understand the unique strengths and challenges of each island. Thanks to the leadership of CHWs in individual states and across the nation, the CHW field has grown tremendously and effected important policy change in recent years. As stakeholders consider new policies to support the workforce and programs to improve the health of vulnerable communities, we believe it is absolutely vital that they engage existing, well-established CHW professional groups and encourage them to lead decision-making processes. During the official launch of the National Association of Community Health Workers, the Conference, the phrase "nothing about us without us" was often used. This call to CHWs is a reminder that they should engage in policy development and advocacy so that their perspectives and wisdom are reflected in all decisions that affect the CHW workforce and the communities that CHWs serve. We encourage CHWs to engage, speak up with their perspectives, and use their voices to advocate for the workforce and their communities!

Conflict of Interest

None of the authors identify a conflict of interest.

Acknowledgments

We are extremely grateful to Joey, Auntie Aloha, Auntie Ulu, Nalani, Yvette, Velma, Lucille and so many other wonderful community health workers from Hui No Ke Ola Pono and the Native Hawaiian Health Care Systems and Community Health Centers across Hawai'i, our HPCA Community Health Worker Advisory Committee, the Wai'anae Health Academy for mentoring and paving the way for community health workers certificate training in Hawai'i, the University of Hawai'i community colleges for partnering on so many community health worker projects, Hawai'i-Pacific Basin Area Health Education Centers for their initial and ongoing support for community health workers. We are also grateful to Jill Guernsey de Zapien, Catherine Haywood, all the members of the Louisiana Community Health Outreach Network, our fellow National Association of Community Health Workers board members, and most of all, the illustrious, creative, devoted, compassionate community health workers across the nation for living their mission, sharing their wisdom, and advocating for the health of their communities.

Authors' Affiliations:
- Founding Board Member, National Association of Community Health Workers, Honolulu, HI (NS)
- Founding Board Member, National Association of Community Health Workers; Department of Behavioral and Community Health Sciences, LSU School of Public Health; Section of Community and Population Medicine, LSU School of Medicine; Center for Health Care Value and Equity, LSU Health Sciences Center- New Orleans, New Orleans, LA (AW)

References

1. American Public Health Association. Support for community health workers to increase health access and to reduce health inequities. 2009. https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/09/14/19/support-for-community-health-workers-to-increase-health-access-and-to-reduce-health-inequities. Accessed June 9, 2019.
2. American Public Health Association. Support for community health worker leadership in determining workforce standards for training and credentialing. https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2015/01/28/14/15/support-for-community-health-worker-leadership. Accessed June 9, 2019.