Building Community Capacity with Community Based Participatory Research in a Native Hawaiian Community

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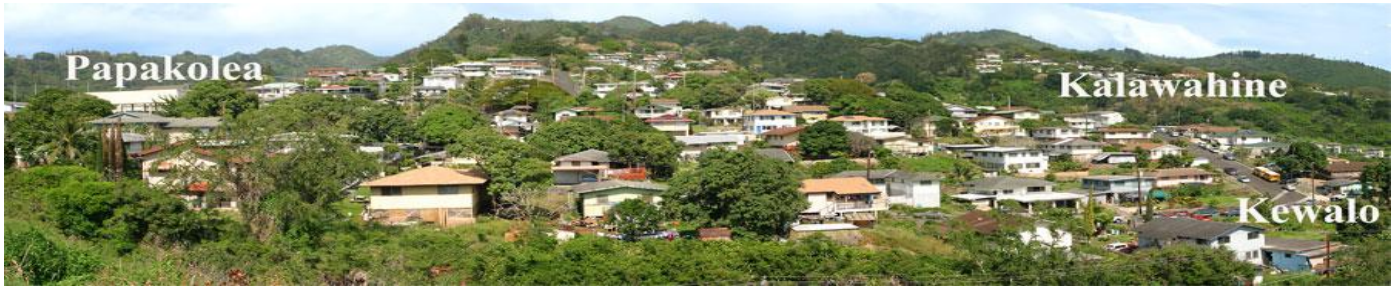

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Introduction

Community Based Participatory Research (CBPR) has been at the forefront of research approaches in the academic community for years. However, getting community to participate in a meaningful way has sometimes been challenging. The CBPR approach can benefit communities in capacity building. Kula no na Po'e Hawai'i representing the communities of Papakōlea, Kewalo and Kalawahine, and other groups representing Native Hawaiians and Pacific Islanders, including Filipinos, joined a successful CBPR project with the Partnership in Lifestyle Interventions (PILI) 'Ohana Program (POP). In time, Kula no na Po'e Hawai'i designed and implemented Kawaihonaakealoha Phase I, a kupuna service project to identify and address the health and safety needs of residents 55 years and older to age safely in place. These projects support the view that CBPR builds community capacity.

Community

The Hawaiian homestead community of Papakōlea, Kewalo and Kalawahine[1] was established on May 16, 1934 under the Hawaiian Homes Commission Act, 1921[2]. Papakōlea is located on the island of Oahu in the heart of its urban core, in the city of Honolulu. Papakōlea covers an area of approximately 177 acres. The land on which we live is mountainous with the

[1] *Papakolea, Kewalo and Kalawahine will be referred to as "Papakolea".*
[2] *In 1921, the federal government of the United States set aside as **Hawaiian Homelands** approximately 200,000 acres (809 km²) in the Territory of Hawai'i as a land trust for homesteading by Native Hawaiians. The law mandating this, passed by the U.S. Congress on July 9, 1921, was called the **Hawaiian Homes Commission Act** (HHCA) and, with amendments, is still in effect today.*

majority of homes built high on the mountainside. House lots tend to be small and are single-dwelling units. The boundaries of our community are Kaululaau Street to the north; Hiilani Street to the west; Kalawahine Place to the east; and Anianiku and Auwaiolimu to the south.

Organization

Kula no na Po'e Hawai'i (KNNPH) is a 501(c) 3 community-based non-profit organization, providing services at the Papakōlea Community Center. KNNPH is governed by a seven-member Native Hawaiian community board with a broad range of experience in business, community development, corporate operations, non-profit management, finance, and education with a mission dedicated to promoting multi-generational learning opportunities that instill cultural diversity and sensitivity. While the board provides policy direction and oversight, KNNPH Executive Director and staff have proven track records of successfully engaging with and working in the Papakōlea community.

Weinberg Fellow

Adrienne Dillard, Executive Director of KNNPH, is a Weinberg Fellow from the class of 1995. Ms. Dillard is committed to serving the Hawaiian homestead communities of Papakōlea and has done so for the past 15 years. In her role, she works successfully utilizing the Weinberg training she received in effective collaboration to build community and organization capacity to meet social, cultural and economic needs. Ms. Dillard oversees and provides a myriad of services in organization programs such as an after school literacy program and the PILI Ohana Program and Kawaihonaakealoha Phase I.

Ms. Dillard works with the Papakōlea Community Development Corporation for operation of the community center and is a board member of Empower Oahu and the Hawai‘i Alliance for Community Based Economic Development. She was president in 2006-2007 of the

Hawai'i Pacific University (HPU) Social Work and Humans Services Student Organization and a member of HPU Social Work Community Advisory Committee. Ms. Dillard is a senior at HPU pursuing a Bachelors of Social Work with an expected completion date of December 2008. Ms. Dillard will enter a Master's of Social Work program in 2009.

Examples of past successful collaboration projects headed by Ms. Dillard for community include, Ku 'Ike Project (Rise Up for Literacy), a partnership between Abraham Lincoln Elementary School and the John A. Burns School of Medicine and Nou Ke Ola (Life is Yours) a partnership between the University of Hawai'i Department of Pediatrics. The partnership between Ke Ola Mamo and Queen Emma Clinics for Ask Kauka was also successful.

One of the most recent health projects occurred through a Hawai'i Export Center Ulu Network Grant, which partnered KNNPH with the Queen Emma Clinics. This project's objectives were to provide awareness, prevention, and control of diabetes in youth. These are just a few of the many successful collaborations that Ms. Dillard has spearheaded on behalf of this organization to improve the health of its community members.

Community Based Participatory Research (CBPR)

Community-based participatory research (CBPR) emphasizes uniting academia with the community as full and equal partners in all phases of the research process. "At the same time, adoption of CBPR principles stressing research *with* rather than *on* communities, affirms the value of communities' experiential knowledge and stresses a collaborative process" (Leung, Yen, & Minkler, 2004).

There is an on-going trend between academia and communities to collaborate in CBPR projects to address health disparities and/or social problems of indigenous and minority populations. Communities want to be included in the design and implementation of projects and

are demanding to be key stakeholders. Some communities still question whether community groups have the capacity participate in research projects as equal partners. KNNPH has been part of two projects that have proven community capacity can be built for equal participation. The PILI ʻOhana Program and the Kawaihonaakealoha Phase I projects are described below.

PILI ʻOhana Program (POP)

"The PILI ʻOhana Program (POP) originated with researchers from five community organizations, a team of academic researchers from the Department of Native Hawaiian Health (DNHH) at the John A. Burns School of Medicine (JABSOM), and five additional community organizations who serve in an advisory role. The POP received a 3-year CBPR planning grant from the National Center on Minority Health and Health Disparities (NCMHD) to: 1) establish a community-academic partnership aimed at obesity-related disparities in Hawaiʻi, and 2) to implement a pilot intervention to address weight loss maintenance (PILI ʻOhana Intervention) in Native Hawaiians and Pacific peoples. The community-academic partnership consisted of a physician, health psychologist, epidemiologist, dietician, public health nurses, behavioral scientists, and research staff who have collaborated closely in the research activities of the 3-year planning grant (Kaholokula, 2007).

Principal Investigators (PI's) participating in this project with the University of Hawaiʻi, Department of Native Hawaiian Health identified the creation of a co-learning environment as a crucial component for success when collaborating with academia. Both the university and community learned together while designing the research model for this project.

The POP had a positive impact on the capacity of all of the organizations at the table since 2005. The original five community organizations in the partnership are: 1) Hawaiʻi Maoli - Association of Hawaiian Civic Clubs (HM-AHCC), 2) Kalihi-Palama Health Center (KPHC), 3)

Ke Ola Mamo Native Hawaiian Health Care System (KOM), 4) Kokua Kalihi Valley Comprehensive Family Services (KKV), and 5) Kula No Na Poʻe Hawaiʻi (KNNPH). These five community organizations reflect three community types: 1) grass root community (KNNPH and HM-AHCC), 2) Native Hawaiian Health Care System (KOM), and 3) community health center (KKV and KPHC).

This was the first experience conducting a randomized controlled trial for KNNPH. All the organizations agree that community and organizational capacity has been built. Four of the five organizations feel individual capacity has increased for those employees and community members participating in this project. Capacity building occurred on three levels organizational, community and individual.

Organizational Capacity Building

POP was the first opportunity for KNNPH as a grassroots community group to manage the budget and the research process with National Center on Minority Health and Health Disparities (NCMHD), National Institute of Health funding through a sub contract with the John A. Burns School of Medicine at the University of Hawaiʻi Manoa. KNNPH completed the necessary paperwork to establish their first Federal indirect rate.

Many agree that there was more at stake in this project because community was at the table from the very beginning. There was an active role for community from the beginning and the engagement did not pertain to funding received. The partnerships that were established from the beginning had an enormous impact on all organizations. "Explicit throughout the CBPR process are the deconstruction of power and the democratization of knowledge. CBPR exposes and challenges the structural powers that oppress groups of people whether subtly or overtly." (Leung, Yen, & Minkler, 2004).

"Consulting with a community includes eliciting feedback, criticism, and suggestions; it does not include asking for approval or permission" (Dickert & Sugarman, 2005). The community groups, were never excluded from the conversation or decision-making. This was especially important to the community groups who felt "we had an active say and was always sought after for our opinions" and "If you missed meetings you were not made to feel like you had to have a passive voice, you had input during the entire process." (Palakiko & Kekauoha, 2007). "Through the process of participation, knowledge becomes democratized such that it is accessible both intellectually and physically, as well as being locally relevant to participants. As a result, participants take equal ownership of the research question and process, making the research outcomes accessible, understandable, and relevant to their specific interests and needs." (Leung, Yen, & Minkler, 2004). This was the experience in Papakōlea.

Human subjects training and obtaining Federal Wide Assurance with the university's Institutional Review Board process were early organizational requirements fulfilled by all entities. Each group met the requirement and identified a Human Subjects administrator. Ms. Dillard has this role on behalf of KNNPH. The organizations are keeping these credentials current to be ready for future opportunities.

In the POP, organizational capacity increased when community organization staff developed new skills such as conducting the informed consent procedure, informant interviews, and focus groups; facilitating the intervention with a group; biophysical measurement with a six-minute walk test, etc.

The organizations focused on progression that requires a more creative path to continue projects and/or programs for its constituents to improve health outcomes. All programs now have more staff comfortable with the research process and data collection – training that will be

used in future research and service projects. There is a perspective that the transferablity of knowledge and the opportunity to build the reputation of their organization heightened the regard for the integrity and accountability of their work.

Community Capacity Building

"Community capacity describes a process that increases the assets and attributes that a community is able to draw upon in order to take more control of and improve the influences on the lives of its members. Interest in community capacity building as a strategy for sustainable skills, resources and commitments in various settings and sectors has developed because of the requirement to prolong programme gains" (Laverack, 2001).

"Community Based Participatory Research (CBPR) lends itself to meet the need of many organizations to assume a more interactive role at the table in research projects while building the capacity of its members" (Laverack, 2001). Community capacity increased when KNNPH (e.g. conducting informed consent, survey interviews, and home assessments; facilitating the training with canvassers; preparing the community report) developed additional new skills.

New relationships developed throughout the POP. There was sharing of resources to insure the success of each site. In addition, sharing challenges and working together toward finding solutions has provided insight into the different communities and organizations. Each site selected and shared an incentive with the others. The monthly Steering Committee meetings provided another opportunity to be supportive of each other's efforts. Meetings moved from site to site.

The POP required that KNNPH conduct a windshield tour of community and outlying areas to determine what resources were available to support the project. We conducted key

informant interviews and focus groups with different community members to obtain needed information.

KNNPH screened 60 potential participants with the following preliminary results:

Screened	Eligible	Eligible and Consented	Baseline Assessments	Completed Lessons 1 to 8 (any order)	Randomized to Family and community intervention	Randomized to phone call follow-ups	Completed 2nd Assessment	Completed 3rd Assessment
60	51	51	51	26	25	17	38	28

Building community capacity is one method KNNPH is using to ensure sustainability of programs as competition for funding dollars increases. KNNPH having collaborated successfully with the Department of Native Hawaiian Health acquired the skills and confidence to take the lead to design and implement a CBPR project, Kawaihonaakealoha Phase I. With the training received during POP, KNNPH was able to take the lead in the design and implementation of our very important kupuna health needs assessment.

Kawaihonaakealoha Phase I

In 2007-2008, Kawaihonaakealoha, "*respectfully submitted with love*," a community-planning project began in our community. This CPBR project sought to increase community capacity while implementing a project to identify and address the health and safety needs of residents 55 years and older. The goal of the project is to plan and provide access to programs that will permit residents to safely "age in place." The first step was to identify the priorities in our community by conducting a health needs assessment survey.

Now, as communities take a greater responsibility for addressing their challenges, they are no longer allowing others to define for them how to obtain successful outcomes to improve their situations. Today, there is a greater expectation that researchers are culturally competent. Community representation can define what information is most relevant to influence significant change.

"More so than ever, the collaborative efforts of community are considered a powerful means of improving community health. These partnerships, voluntary collaborations of diverse community organizations that join forces to improve community health, can enhance organizational and personal relationships in the community and thus promote the health of residents" (Hasnain-Wynia, Margolin, & Bazzoli, 2001).

Some research encounters require skills that are not readily available in communities. Communities continue to be concerned about whether they can develop the skills needed to make their involvement in research projects valuable. The average citizen has many of the skills required for successful outcomes in a project with training. There is an under estimation of the ability of community to come to the table as lay people and build their capacity for research.

Although KNNPH had staff with interviewing and focus group skills from participation with POP, their capacity increased with the submission of the IRB application for Kawaihonaakealoha Phase I. This new project required KNNPH to develop the consent forms and marketing tools, which had been done by the DNNH for POP.

This project began in our community because of the work of Paula Higuchi, a MSW student from University of Hawai'i whose practicum site was in Papakōlea with KNNPH. Her work with our kupuna provided an insight for the need to obtain more information on the concerns that were not being addressed. As a result, a grant was submitted to the Office of

Hawaiian Affairs to embark on this undertaking that sought to identify and address the health and safety needs of residents 55 years and older.

Our approved IRB application to the University of Hawai‘i named Ms. Adrienne Dillard, Executive Director of KNNPH and Paula Higuchi as the co-principal investigators. As a Weinberg Fellow, Ms. Dillard continues to focus on the teachings that advocate for successful collaborations as a key to leverage limited resources.

Our partners in phase I included Ha Kupuna, the National Resource Center for Native Hawaiian Kupuna at the University of Hawai‘i Manoa, Ha Kupuna provided the linkage to the University of North Dakota (UND), training for the community canvassers, and conducted the data analysis of the environmental scans. The National Resource Center on Native American Aging at the University of North Dakota provided us with the Elder’s Survey III (attachment 1). UND provided us with the opportunity to offer suggestions to make the survey relevant by including the Native Hawaiian population. There were no questions specific or inclusive of the Native Hawaiian population prior to our participation.

Capacity increased with new community engagement processes. We needed the target population to want to participate in completing the health assessment surveys. Therefore, we did personal invitations to key community stakeholders for meetings to introduce the project. The community outreach used new approaches in order to engage community.

Individual Capacity Building

The initial response to our call for help resulted in over 30 residents coming to our first meeting to obtain an overview of our project. After our second meeting, 12 had committed to assisting with this project by becoming community canvassers. Our canvassers attended a number of meetings for training and status updates as our project progressed. Their service was invaluable as

they provided a direct link to family and friends. Our canvassers went door-to-door, spoke with neighbors on the bus, ensuring everyone had the opportunity to participate in this project.

A community canvasser assisted those kupuna who selected to complete the survey through a face-to-face interview. Community canvassers were residents of community who were trained to conduct the face-to-face interviews of ohana and friends to assist with the completion of the surveys. The 2-part survey took about an hour to complete. Every participant who completed the survey was given a small makana (gift).

Youth in the afterschool program assisted with data cleaning and community mapping of the results (attachment 2). The middle school age students received stipends for their participation. Training was provided to each on the computer and/or copier.

Now, our most productive community canvasser is employed as the part-time Research Assistant for the POP project. Initially, she thought she lacked the skills necessary to fulfill the position requirements, however, she had acquired a new skill set as she canvassed community. As Research Assistant, she facilitates classes, data collection and is the primary point of contact for participants.

Prior to beginning the survey, each kupuna completing the survey was required to sign a consent form. The consent form provided a description of the project, as well as provided assurance that their responses would be kept confidential; names will not be attached to individual responses, participants could decline to answer any question and terminate the interview at any time.

The community was part of determining what the research project would entail and wrote the proposal. Roles were defined from the start with community and university responsibilities being agreed upon. Meetings have been conducted to present our finding to a kupuna group, community canvassers, community leaders and community residents. The community report

(attachment 3) has been mailed to each home and all of our community partners. Various community members were asked to review the report. We determined that our report would not go to print without a kupuna who was the Papakōlea Community Association president for over 20 years providing final approval. We did not expect that there would be concerns over community wanting to write their first report without the assistance of university partners. The community report required a host of community members to participate in the process as writers, reviewers, and photographers.

This was the first time KNNPH had taken on a project of this magnitude and it was very important that the community owned not only the data, but also the process under which the data would be presented to community.

Expanding one's experience to include research as a new area of personal development coincided with several of those involved. KNNPH now has a consortium of community peer educators in their traditional practioner students. Ms. Dillard returned to school to pursue a degree in Social Work, while another began pursuing a certificate in non-profit management. All have increased the organizational, as well as their personal capacity to conduct research.

This project supports findings that many "community based research projects are designed in ways that enhance the capacity of the community-based participants in the process" as stated by the Detroit Community Academic Urban Research Center community based public health principles. (Lantz, Viruell-Fuentes, Israel, Softley, & Guzman, 2007).

Conclusion

As we look to the future, Kawaihonaakealoha Phase II proposes partnerships that will support a community defined case management approach to address physical and environmental needs, through a service-learning curriculum allowing students to learn culturally appropriate

care from community, while providing needed case management services to kupuna. KNNPH's participation in this project will help address major concerns for our families and communities, which is a great opportunity for this organization. It will also provide valuable insight into the effectiveness of community based partnerships for addressing health disparities issues in an indigenous population.

We received surveys from over 200 kupuna in our community, with 90% being Native Hawaiian. Our survey assessed the health, utilization of social services (Elder Survey III), and home safety and what changes were needed (Environmental scan) for the kupuna to "safely age in place". Our findings determined 1) which early detection services kupuna access; 2) barriers to accessing services; 3) how kupuna manage chronic diseases; 4) awareness of community services available; and 5) environmental issues.

Our information combined with other participating tribes serves as a powerful advocacy and educational tool for increasing knowledge of American Indian, Alaska Native, and Native Hawaiian elders on health and social status. As part of Cycle III of Identifying Our Needs: A Survey of Elders III, our data is part of 119 service areas representing 298 indigenous nations. Our UND partnership provided us with results from our community, the aggregate tribal data and the U.S. general population data for the survey questions. We learned that many tribes have been able to use this data to advocate, plan, and strengthen funding applications to address the needs of their elders. We plan to do the same.

The planned community-university outreach team concept combines the ecological and system theory model to focus on the individual, his or her situation, and the effect of illness on the system and environment. This systematic approach helps the team to understand that culture is not static; generational differences between kupuna, adults and children are fluid with direct

effect on elderly care. Traditional values of caring for kupuna in community cannot be replaced with institutional care, creating dissonance between traditional cultural values and modern realities.

KNNPH remains part of the PILI Ohana Program, which has been funded for an additional 5 years starting July 1, 2008 to address obesity-related disparities. This CBPR project will be a more definitive weight loss maintenance study of the targeted populations utilizing a 3-arm (two interventions and a control group) randomized control trial. KNNPH is one of four community organizations that will continue in this next phase of the project.

The Weinberg Fellows Program training that continues to be utilized by Ms. Dillard has made her proficient in creating effective collaborations/partnerships and fiscal accountability. An effective non-profit organization should not try to do everything on its own. You can make the impossible possible with the right partners at the right time. It does not always have to be about money. We all have something that we can offer each other. We want to collaborate with organizations that are willing to come to the table as equal partners. Key to successful collaboration is a willingness to combine complementary assets to achieve a common goal. Collaborations should be beneficial to all involved. Community Based Participatory Research is a useful approach for successful collaborations that builds community capacity.

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